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ABSTRACT

This National Council on Disability (NCD) report describes the nation's progress in advancing public policies to increase the inclusion, empowerment, and independence of people with disabilities of all ages, consistent with the vision of the Americans with Disabilities Act of 1990. The report covers December 2000 through December 2001. It reviews federal policy activities by major issue areas, noting progress where it has occurred, and making recommendations. Progress is evaluated in the following areas: (1) disability statistics and research; (2) civil rights; (3) education; (4) health care; (5) long-term services and supports; (6) youth; (7) employment; (8) welfare reform; (9) housing; (10) transportation; (11) assistive technology and telecommunications; (12) international issues; and (13) homeland security. On education, the report concludes that despite widespread noncompliance with the Individuals with Disabilities Education Act (IDEA), the U.S. Department of Education has made only limited use of enforcement through its sanction authority. NCD recommends that Congress authorize and fund the Department of Justice to investigate and litigate IDEA cases independently. NCD also recommends that the IDEA budget appropriation include a 10% set-aside provision for complaint processing. Part 2 of the report describes major activities of the NCD for fiscal year 2001. (Contains 130 references.) (CR)

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NATIONAL DISABILITY POLICY: A PROGRESS REPORT

December 2000–December 2001

National Council on Disability
July 26, 2002

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National Disability Policy: A Progress Report
December 2000—December 2001

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NATIONAL COUNCIL ON DISABILITY

An independent federal agency working with the President and Congress to increase the inclusion, independence, and empowerment of all Americans with disabilities.

Letter of Transmittal

July 26, 2002

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit NCD's *National Disability Policy: A Progress Report*, as required by Section 401 (b)(1) of the Rehabilitation Act of 1973, as amended.

This report covers the period from December 2000 through December 2001, the end of the first session of the 107th Congress. It reviews federal policy activities by issue areas, noting progress where it has occurred and making further recommendations where necessary to the executive and legislative branches of the Federal Government.

Disability is not the experience of a minority of Americans. Rather, it is an experience that will touch most Americans at some point during their lives. Today, more than 54 million Americans have disabilities, a full 20 percent of the U.S. population. About half of these individuals have a severe disability, affecting their ability to see, hear, walk, or perform other basic functions of life.

Significant barriers, however, still exist for individuals with disabilities who try to participate fully in American society. People with disabilities want to be employed, educated, and active citizens in the community. Unfortunately, on average, Americans with disabilities have a lower level of educational attainment and are poorer and more likely to be unemployed than those without disabilities. In today's global economy, America must be able to draw on the talents and creativity of all its citizens.

In your New Freedom Initiative, you laid out a blueprint to increase investment in and access to assistive technologies and a high-quality education and to help integrate Americans with disabilities into the workforce and into community life. This initiative comes at a time when many disability advocates are expressing concern about the future of disability policy. NCD will work with your Administration and Congress to ensure that every individual with a disability has access to the American dream.

With strong, representative, and experienced leadership and open, ongoing input from the disability community, we can meet the challenge to make the most of the opportunities facing us

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at the start of your new Administration. NCD has completed over the past several years civil rights policy evaluations directly related to the disability policy areas addressed in the New Freedom Initiative. NCD invites you and your Administration to draw on the research and studies conducted by our agency for information on how and where executive agencies can act to the maximum benefit of their consumers.

NCD stands ready to work with you and stakeholders inside and outside the government to see that the public policy agenda set out in the attached report, in *Achieving Independence*, in a series of civil rights monitoring studies published as NCD reports, and in the New Freedom Initiative is implemented.

Sincerely,

Marca Bristo
Chairperson

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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PART I

Executive Summary

Introduction. The National Council on Disability's (NCD) 2001 annual progress report marks a turning point in public policy, with the advent of a new national Administration. Such moments in our history not only offer great hope for innovation and reform but also require a sense of continuity, necessitating perspective and awareness of what has come before and a recognition of the continuity and complexities underlying policy in all spheres.

To help link the past and the future, NCD provides an overview of some of the major public policy initiatives in disability during the decade of the 1990s. These initiatives can be grouped in three areas: civil rights, service delivery programs, and technology. Although the various works differ in accordance with their goals and contexts, the body of work constituting the statutory record of the 1990s reflects an overarching and unifying conceptual framework that gives the laws much in common.

Among the key features these diverse laws have in common are the recognition that issues of concern to Americans with disabilities, such as the design of our public buildings and communications infrastructure, can no longer be addressed in isolation from the general society; the fact that consumer participation is a key element in the effective operation of all programs and laws; the awareness that advocacy resources and technical assistance are critical to the success of all initiatives; and the belief, in areas ranging from employment to education to housing, that society benefits by the inclusion of Americans with disabilities in the mainstream institutions of society.

The laws have also recognized that the allocation of the costs of nondiscrimination and inclusion are often as important as any assessment of the total amount of such costs. For that reason, the laws also have in common various mechanisms aimed at ensuring that the burden of access and equality will not unduly fall on a narrow range of institutions or entities. Equally, the costs of

policy not only must be reckoned in the sense of what is required to achieve various goals but also must include a sophisticated awareness of both the costs of inaction and the indirect benefits of various measures and strategies.

NCD has played an important, ongoing role in identifying issues and barriers, bringing key actors from within and without government together, and providing objective, unbiased data from which policy can be reliably derived or better understood. This role is discussed from a historical standpoint and as it relates to the demands of this new era.

If continuity is important, it must alert us to our collective failures as well as remind us of our successes. A series of NCD reports has documented failures in enforcement across a broad spectrum of programs and laws. Without credible enforcement, even the best laws become ineffective. Just as we know that laws in other areas are not self-executing, so must we carry this awareness into the disability policy arena. With energetic enforcement, the sincere efforts of most can be honored, the dereliction of the few can be addressed, and the goals of public policy can be effectively and consistently advanced.

Census 2000 and Disability Statistics. Problems continue to be associated with widely used disability employment and other data, including issues surrounding the collection and analysis of relevant and reliable statistical data on America's population with disabilities.

The findings of the 2000 Census, together with those of other compilations relating to the employment status of Americans with disabilities, have been severely questioned on methodological and validity grounds. The accuracy of these data are critically important in an era of evidence-based policy because misleading information can lead to misguided or premature public policy decisions.

Federal agencies extensively use and underwrite the costs of disseminating a great variety of disability data. Whereas people should be entirely free to use whatever data and data sources they

see fit, public money should not be used to support the dissemination of suspect findings and conclusions.

Similarly, in other areas of disability research, new barriers have emerged to the collection and analysis of reliable data. These barriers range from the new definitions of disability crafted by the courts under various statutes to the problems associated with measuring function as it relates to employment, education, or independent living when assistive technology is taken into account.

The report recommends that the Federal Government review and rationalize the range of statistical efforts and test proposed new measurement techniques and research practices to ensure their reliability before they are put into widespread use.

Civil Rights. A perceived hostility toward disability on the part of the courts, congressional proposals that would treat disability civil rights laws differently and more harshly than any other laws, and other factors have combined to create a sense of great unease and fear among America's population with disabilities. In light of persistent under enforcement of civil rights laws and lax monitoring of the requirements of service programs, the report examines each of the major areas where erosion in civil rights protections has occurred or is seriously foreseen.

Major areas addressed and explained are court decisions dramatically restricting the applicability of the Americans with Disabilities Act (ADA); lack of coordination among agencies or of material progress in key enforcement areas identified over recent years as needing reform; failure to include persons with disabilities among those protected by hate crimes laws; failure to stem genetic discrimination by employers and insurers that disproportionately affects persons with hidden disabilities; the need for continued outreach to people with disabilities from diverse cultural groups who face cultural, linguistic, and other barriers to full participation in society and who interact with the issues posed by societal reactions to their disabilities; court decisions outside the ADA that adversely impact access to the courts by persons with disabilities and, in the aggregate, can be characterized as reflecting a closing of the courts to individual citizens; and

the need for greater outreach to the disability community by the Department of Justice in formulating its interventions through amicus curiae briefs in Supreme Court and other major federal court cases involving the rights and interests of Americans with disabilities.

Education. As the Individuals with Disabilities Education Act (IDEA) faces reauthorization, we must carefully assess the implications of our approach to education for students with disabilities and sensitively apply the policy initiatives central to the No Child Left Behind Act (NCLBA)—the reauthorization of the Elementary and Secondary Education Act. At the same time, the successes of special education should not be overlooked, and the widely documented need for more effective monitoring and enforcement should be borne in mind under any revised framework.

In addition to the issues surrounding implementation of NCLBA and a review of NCD's comprehensive IDEA assessment study, NCD specifically deals with the charge of the President's Commission on Excellence in Special Education; the key issues and controversies involved in IDEA reauthorization, including student discipline; minority overrepresentation among students receiving special education services; parental involvement and due process; use of assistive technology; universal design and access to mainstream school technology, instructional materials, and media; disability harassment; full funding; and accountability of schools for the educational outcomes of special education students.

Health Care. NCD has a long record of activity, research, and involvement in the area of health care and access to medical resources and services. Against this background of interest and expertise, the current congressional and national debate over the Patients' Bill of Rights raises important questions for what inclusion means for people with disabilities in the health care realm.

In connection with this proposed legislation, the report identifies issues and offers analysis and recommendations concerning coverage of all privately insured persons; access to specialized

care; point-of-service options; continuity of care; standing referrals; timely and accurate information, including accessible information, regarding details of coverage and available options for treatment; access to clinical trials and availability of clinical trials for assistive technology or other nonpharmaceutical interventions and modalities; grievance procedures; medical necessity determinations; and mental health parity.

Beyond this proposed patients' rights legislation, the report deals with the status of efforts to identify and treat persons with mental health conditions in the criminal defendant and prison population; the problem of balancing pain-relief promotion with the avoidance of assisted suicide; the need for reforms in Medicare and the procedural vehicles available for carrying out the necessary review of current program rules; and the potential applicability of telemedicine to persons with disabilities, who are likely to be among its most frequent users.

Long-Term Services and Supports. Taking the unprecedented interagency effort culminating in the Department of Health and Human Service's December 2001 *Olmstead* implementation report as its point of departure, NCD reviews the Administration's continuing support for the Supreme Court's *Olmstead* decision and draws out implications; analyzes the major premises of the report as a basis for clarifying the issues and options it raises; discusses the economics of *Olmstead* as these relate to national policy favoring institutional versus community-based living and care for all Americans, including those who are elderly and those of a younger age with disabilities; discusses some of the other, specific programmatic initiatives addressed in the report and in other expressions of Administration policy; considers the implications of broad-based policy changes favoring community-based and in-home services and care for the private long-term care insurance and other non–Medicaid recipient populations; and addresses the role of Social Security Disability Insurance (SSDI) and other programs of particular concern to people with disabilities in the context of social security reform.

Youth. Although such issues as housing, education, health care, and even employment are important for everyone, within each of these areas are some subjects of particular concern and

importance for our youth with disabilities. One key example is school-to-work transition services, as required by both the federal Rehabilitation Act and IDEA. Widely recognized to be inadequate, despite notable successes in certain localities, these services are crucial for the ability of students with disabilities to enter adult services and employment after leaving school.

NCD discusses chronic transitioning problems and suggests several remedial approaches, such as establishing system-to-system continuity in the availability of assistive technology; cost-shifting between rehabilitation and education agencies; and the implementation of joint accountability between the service systems for the success of transition services and programs.

Employment. As it is for society as a whole, employment is a cherished goal for most Americans with disabilities, but one that continues to elude all too many. Implicating the education, vocational training, health care, and transportation systems as they do, the barriers to increased employment for people with disabilities are as complex and multifaceted as those faced in any area of policy, even as enhanced employment becomes the ever-more central objective of so much public policy in the disability area.

For this reason, NCD's discussion of this subject begins with an appraisal of the importance of interagency coordination, focusing particularly on the potential of the new Office of Disability Employment Policy to spearhead the necessary effort. Related to the discussion of statistics, NCD also examines the sources and role of statistics in the employment policy sector.

Major new initiatives in employment policy are also dealt with, including issues surrounding the implementation of the Ticket to Work and Work Incentives Improvement Act; recent federal hiring initiatives to expand opportunities for persons with psychiatric disabilities; federal initiatives to ensure the availability of information about the provision of reasonable accommodations in governmental employment; and concerns regarding the accessibility and responsiveness to work-aspirants with disabilities of the resources and services of one-stop career centers.

From the standpoint of the broadest possible perspective, two other issues are covered: the proper role of the Federal Government in ensuring that those operating under federal contracts, grants, or licenses adhere to principles of nondiscrimination and accessibility; and the role of employment tax incentives for both workers with disabilities and businesses in stimulating opportunities and heightening the prospects for success and job tenure.

Welfare Reform. As Congress and the nation prepare to fashion this year the reauthorization of the 1996 welfare reform law, a number of questions about the intersection between welfare and disability, as well as about the use and coordination of resources, emerge as needing discussion and answers. To the degree that states are obliged to meet return-to-work and related targets under the welfare system currently in effect, NCD notes that effective identification of recipients with disabilities and coordination with other programs in meeting their needs can contribute to the ability of states to meet their employment goals. Such attention can also facilitate the effective entry into employment of persons with caretaker responsibilities for children or other family members with disabilities.

NCD recommends that the new law include clear provisions, incentives, and mechanisms to assist state welfare reform systems in reaching out to vocational rehabilitation, developmental disabilities, and other programs to identify and marshal the resources and expertise that will contribute to the quality of work with persons with disabilities among those receiving or at risk of needing welfare supports.

Housing. Housing plays a role in every aspect of people's lives, from the amount of discretionary money available for meeting other needs to the time and distance involved in going to work to the quality and availability of a wide range of community resources. Affordable housing is in short supply for many Americans, but for people with disabilities, the scarcity is exacerbated by inaccessibility and all too often by discrimination.

Based on the definitive findings of its November 2001 report *Reconstructing Fair Housing*, NCD reviews the status of fair housing and equal opportunity laws and practices, including the organization of the fair housing laws' enforcement effort; complaint-handling and case-processing procedures; funding of fair housing resources; enforcement of fair housing laws; mediation alternatives to litigation; disposition of aged cases that have remained unresolved in the enforcement system for prolonged periods of time; and such related matters as the role of "visitability" in housing policy and the benefits to be expected from the Department of Housing and Urban Development's (HUD) fair housing survey.

The progress report then addresses related issues, such as means for increasing the supply of affordable and accessible housing; expanding the use of housing vouchers; and stimulating home ownership, including proposals to galvanize market forces on behalf of accessible design; and providing incentives for the availability of mortgage financing for persons with disabilities.

Transportation. For many Americans with disabilities who cannot drive or who, if they could drive, do not have the resources for the adaptive driving controls, lifts, telescopic systems, or other assistive technology that may be necessary, accessible transportation represents one of the chief barriers to participation in economic and community life.

Air travel presents its own set of vexing issues. Implementation of the Air Carrier Access Act has long involved a delicate balancing of nondiscrimination and security concerns. In the wake of the tragedy wrought by terrorism in September 2001, implementation of this law has become all the more difficult and, at the same time, more and more important.

NCD describes the issues that have emerged and the problems reported around the country by air travelers with disabilities, many of whom have been inconvenienced and some endangered by misapprehensions and suspicions on the part of security screening personnel that appear to have little to do with the imperatives of security. NCD recounts these concerns, based on the reports reaching it, and makes proposals for additional measures on the part of the Department of

Transportation (DOT) to ensure that the ability of Americans with disabilities to travel by air will not be unduly restricted.

Although agreements and requirements have been set in place for establishing timetables and performance standards for the implementation of accessibility for travelers with disabilities on intercity buses, grounds exist for concern regarding the speed, adequacy, and universality of compliance. NCD discusses these concerns and makes recommendations for the follow-up and monitoring necessary to make certain that the legal and societal expectations in this area are met.

NCD also makes recommendations for improved collaboration between the Department of Justice (DOJ) and the DOT in the implementation and enforcement of civil rights laws bearing on transportation. NCD's major report on the ADA, *Promises to Keep*, disclosed significant shortcomings in the ability of the DOJ and DOT to work together in enforcement, including the DOT's referral of cases to the DOJ when other methods for solving problems proved unavailing. As in other areas of the law, enhanced coordination plays a large role in enforcement, and methods for increasing this coordination are at hand.

The President's New Freedom Initiative discusses some of the transportation issues affecting people with disabilities and was followed up by budget recommendations for a variety of pilot demonstration and competitive programs aimed at improving transportation access and options for people with disabilities. Regrettably, some of these initiatives did not meet with initial approval by Congress. NCD recommends that Congress reconsider its decisions in this area and delineate a range of transportation strategies and modalities that these innovative programs ideally ought to include.

Although we travel today much as we did 50 years ago, research and innovation in transportation are emerging as important elements of our future. Innovative personal transportation vehicles are being introduced and will come into greater use with time, but by no means is it certain that these innovations will prove as meaningful to people with disabilities as they could. To maximize their

relevance to all Americans, NCD makes recommendation for the testing and evaluation of these new devices and designs by and with people with disabilities so the developers can be informed, at a time when modifications in the service of accessibility should still be possible, of the extent to which these devices currently and prospectively can meet the needs of persons with disabilities.

Paratransit remains a concern for many of its users, according to anecdotal reports coming in from around the country. NCD recounts the most frequently heard of these complaints and problems and makes suggestions for how these services can be monitored and improved.

Technology and Telecommunications. Giving birth to what we call the information society, the so-called technological revolution has changed our lives more dramatically and irrevocably than almost any other force or set of developments. Whereas the general assumption is that this is a democratic revolution with benefits and opportunities for all, for many people with disabilities some new technologies are as much or more a barrier to than a source of access and inclusion. The cellular telephone is a great boon to many, but for people who use hearing aids, problems of incompatibility have made cell phones largely inaccessible and unusable. The graphical user interface has vastly enhanced access to high-speed data and pictures, but if Web sites are not designed with persons who use speech access in mind, these ubiquitous technologies become impenetrable walls blocking access to the wealth of information and opportunity the Web conveys.

Because the implementation of Section 508 of the Rehabilitation Act in mid-2001 was a watershed for assistive and accessible technology, NCD reviews the experience of operating under this statute thus far and discusses the issues that have emerged in the operation of the law to date. NCD makes proposals for oversight, technical assistance, and outreach and discusses the applicability of the law to telecommuting by federal employees.

Distance learning has made the benefits of education and training available to many people who could not otherwise obtain them. But again, these benefits may prove illusory to computer users with disabilities unless accessibility is taken into account in the design of the software and course materials. Based on the work of a national commission, NCD discusses the issues involved and makes continuing recommendations designed to ensure that no one is excluded from the promise of this new modality.

The so-called e-rate, providing grants and subsidies for Internet access to schools and libraries, is one of the most important innovations of the Telecommunications Act of 1996. But those entities receiving such subsidies or cash grants have not been required to make their resources accessible to students or library patrons with disabilities. NCD reviews the history of efforts to correct this and calls on the Federal Communications Commission (FCC) to propose reforms.

Another key provision of the Telecommunications Act is Section 255, which requires telecommunications equipment and services to be accessible to individuals with disabilities where readily achievable. Based on research and experience under the law, NCD identifies a number of barriers to its effectiveness and recommends reforms in such areas as enforcement and the apparent distinction the law makes between voice communication, which is covered by the law, and the communication of data or pictures, which appears not to be covered by it and hence is subject to no accessibility requirements. NCD offers recommendations for studying and remedying this anomaly.

A wide variety of activities are encompassed under the concept of e-government. NCD discusses the implications, achievements, and management of the variety of measures and strategies involved as they relate to access to governmental information and programs by persons with disabilities.

Recent developments in copyright law may bring intellectual property and disability access rights into collision in cyberspace. NCD describes the sources and implications of this conflict

and requests clarification of the law from the appropriate administrative agencies as a first step in determining whether further legislation is required.

Among the many agencies and actions praised in the report, NCD takes note of the FCC's opening of a proceeding aimed at reviewing the temporary statutory exemption of wireless phones from coverage under the Hearing Aid Compatibility Act of 1988. NCD expresses confidence that this will result in the exercise by the FCC of its statutory discretion in favor of requiring that such phones be brought under the coverage of the law.

With the Assistive Technology Act of 1998 scheduled to sunset on September 30, 2002, NCD reviews the unique role played by the programs operating under this small but highly instrumental law, notes the needs that would go unmet if the program were to be abolished, and recommends reauthorization of the law.

International. With full recognition of the many critical issues competing for the attention of American foreign policymakers and with full regard for the balancing that must underlie so many foreign policy decisions and initiatives, NCD reiterates recommendations for the incorporation of disability rights, alongside women's rights and respect for diversity, in America's foreign policy commitments. In particular, NCD offers recommendations to support inclusion of Section 504-like antidiscrimination provisions.

NCD also discusses and will participate in development of a United Nations (UN) convention on disability and recounts awards made at 2001's commemoration of the International Day of Disabled Persons, praising the awardees and expressing confidence that the new Administration will produce its own generation of honorees.

Homeland Security. Sadly, no discussion of public issues can be complete today without a recognition of the imperatives of security. Based on reports and concerns expressed from around the country, NCD expresses a number of concerns regarding the ability of people with

disabilities to obtain key security information or to participate fully in community responses to emergency situations. For the most part, these dangers can be avoided by simple planning, but addressing them should be part of the overall emergency preparedness planning process.

Introduction

The advent of a new national administration is an opportune time for looking forward, but new approaches and innovative policies are not created in a vacuum. For the sake of the lessons learned and to understand the historical and programmatic context in which to make new policy initiatives or corrective systemwide decisions, looking forward must include some looking back. Only with perspective on what has been accomplished as well as what has not been achieved can we begin the process of building consensus around what remains to be done.

An enormous amount of activity, and an impressive legacy of achievement in enhancing equality and opportunity for Americans with disabilities, constitute the data from which we derive both perspective and prospects. The past decade has been a period of remarkable accomplishment and energy in the articulation and expansion of civil rights, employment and educational opportunity, technology access, and, perhaps most of all, attitudinal change around disability in our society.

In concert and cooperation with other federal agencies and partners in the nonprofit and private sectors and with the commitment and participation of individuals and organizations in the disability community, the National Council on Disability (NCD) is proud to have played a role in the development and growth of a bipartisan consensus for opportunity and inclusion. In reports, recommendations, and performance reviews, NCD has helped to frame the debate, made detailed recommendations for change, and monitored the efficacy and enforcement of a variety of programs and laws. NCD has sought to serve as a catalyst to progress, a bridge builder among sectors and stakeholders, and a source of reliable information and tempered judgment in the identification of barriers and in defining the form necessary changes should take.[1]

What has characterized the work of the 1990s? Foremost in the record of the past decade are major legislative achievements in several areas. Principal among these areas are civil rights, service delivery, and access to technology. Overarching and unifying this legislative record are two dominant and recurring themes: (1) people with disabilities deserve the same opportunities

in society as everyone else, and (2) decisions society makes about broad issues of policy, ranging from health care, housing, and education to telecommunications and transportation, inevitably affect people with disabilities just as much as they do everyone else. People with disabilities must be involved in leadership roles in policymaking and implementation processes.

CIVIL RIGHTS

Symbolically, the decade began in 1990 with the enactment of the Americans with Disabilities Act (ADA),[2] which has often been referred to as the landmark civil rights statute for people with disabilities. Dealing with employment,[3] access to state and local government services,[4] and access to public accommodations,[5] the ADA barred discrimination on the basis of disability and established the obligation of mainstream public and private institutions to reasonably accommodate persons with disabilities.

While controversy surrounds some aspects of ADA implementation and enforcement, few would dispute that the law has had a profound effect, both in terms of creating opportunities to learn, work, and participate in society for many people with disabilities and as a spur to institutional and attitudinal changes in all sectors of our society. The wheelchair lift on city buses or the braille signage in the elevators of major buildings testify not merely to our creation of a more accessible environment but more broadly to the changes in attitudes and awareness that have marked this era.

As our awareness of people with disabilities has grown, so has our understanding of the range of situations in which their interests, opportunities, and civil rights hang in the balance. Through the development of our awareness and because of advances in technology, the meaning of access has come to be redefined. This redefinition has been embodied in a number of important new laws, including Section 255 of the Telecommunications Act of 1996[6] (requiring telephone equipment and services to be accessible to people with disabilities) and Section 508 of the Workforce Investment Act of 1998[7] (mandating that electronic and information technology bought and used

by the Federal Government for use by federal employees or members of the public be accessible on terms of equality to all persons, irrespective of disability).

These and other civil rights statutes of the decade have many features in common, but their chief unifying element lies in the recognition of the indispensability of what is best called accessible or universal design. This means that these statutes recognize the impossibility of fully integrating people with disabilities into mainstream society without the buildings, facilities, communications infrastructures, and institutional practices and policies of a variety of entities being designed and implemented with all potential participants and users in mind. Thus, although once it may have been appropriate and sufficient to create jobs in sheltered, segregated settings for people with disabilities, today we understand that only the mainstream economy can provide the resources and rewards necessary to create and sustain the needed range of opportunities and that the competitive economy is where all willing and able workers should be employed. Although formerly we created overly restrictive instructional settings for children with disabilities, now we know that mainstream, integrated settings are the educational venue of choice for a majority of our children. And although once we devised purpose-built, "dedicated" devices—ranging from braille typewriters to hearing aids—to accommodate the communication needs of persons with disabilities, now our laws have come to recognize that participation in the communications environment of today cannot be achieved or preserved by these approaches alone but requires that the entire information infrastructure be designed and deployed with accessibility and usability in mind.

In many ways, the World Wide Web is a metaphor for the 1990s. As such, it illustrates the need for accessible design of mainstream environments if assistive technology (AT) is going to be effective in securing access to the Internet for people with disabilities. The guidelines implementing Section 508 therefore contain detailed information on the functional requirements governmental Web sites must meet in order to be deemed accessible. A number of prestigious private sector organizations have also provided accessibility guidelines[8] and accessibility assessment tools.[9] The Web brings a world of information onto a computer and has enriched the

lives of many with disabilities. Yet, technology creates challenges of its own. For example, the brilliant graphics that add life to many Web pages can make it difficult for a person with visual impairments to get the information he or she needs from a Web site. Now, through application of Section 508 accessibility standards, federal agencies must include descriptive text with Web page images. As another example, the captioned video Web casting that brings live events to a desktop computer can make it possible for a person who is deaf to follow the proceedings.

Even in this time of unprecedented national crisis and peril, our commitment to the maintenance of moral as well as practical balance can be glimpsed in the issuance of a fact sheet by the Federal Aviation Administration (FAA)[10] providing guidance on application of the Air Carrier Access Act (ACAA) (which provides for nondiscrimination against persons with disabilities in air travel and in airport services and practices) to our new airport security imperatives. The fact sheet reinforces the continued applicability of the ACAA, while making clear how its application is necessarily conditioned by the need for dramatically heightened air travel security under current world conditions.

Yet another archetypal statute of the 1990s demonstrates the evolution in our notions of what equal access means and our parallel recognition of the role of technology in bringing this equality of access about. In 1990 Congress enacted the Television Decoder Circuitry Act,[11] which required virtually all TVS sold in America to be equipped with a closed-caption decoder chip. This chip ensures that all TV watchers can access closed captioning, whether they are deaf or not, and that they can do so without the necessity of spending several hundred dollars to buy and install a separate decoder box. The Decoder Act created a new market for captions, as anyone who has ever attempted to watch TV in a crowded sports bar or noisy airport well knows. It has probably also saved more than one relationship by allowing the partner who likes to watch TV late into the night do so without disturbing the sleep of the partner who hates noise.

By itself, the Decoder Act could not create or guarantee the existence of captioned content. For that, the law had to go further, requiring (as the Federal Communications Commission [FCC] did

under the Telecommunications Act of 1996)[12] that major TV networks provide specified amounts of captioned programming.

In our nation's heightened commitment to technology as a tool for increasing employment and enhancing the productivity of our economy, the role of assistive technology as a means for increasing employment opportunities for persons with disabilities has not been overlooked. Most recently, this commitment has been taken up in President Bush's New Freedom Initiative (NFI).[13] Measures aimed at ensuring the accessibility of mainstream technology to people with disabilities and measures for ensuring the compatibility of mainstream with assistive technology will remain indispensable components of our strategy.

Likewise, in areas where technology does not necessarily mediate access and participation, our approach to the articulation and enforcement of civil rights has partaken of the same values. For example, in housing, a slowly evolving thrust of policy has been in the direction of making our nation's overall housing stock accessible to the maximum extent possible. So also in long-term services, our growing commitment to community living and deinstitutionalization for all has extended to older Americans and Americans with disabilities alike.

Everywhere then, in sphere after sphere, the recognition has taken hold that Americans with disabilities have the right to equal access and full participation and that the design of programs, facilities, and systems must take the rights, needs, and legitimate aspirations of these Americans into account.

SOCIAL LEGISLATION AND HUMAN SERVICE SYSTEMS

Through federal-state partnerships, our nation operates a number of service systems designed to provide educational and vocational rehabilitation (VR) and other services to people with disabilities. Based on the recognition that people with disabilities need interventions and service inputs that people without disabilities do not need but that have not historically been provided

within the general labor market and public educational program frameworks, these programs can perhaps best and most generally be described as intended to create a level playing field for Americans with disabilities. These programs have been influenced in fundamental ways also by the values of integration and equality that have come to the fore in the past decade. The Individuals with Disabilities Education Act (IDEA), as substantially revised in 1997,[14] most graphically demonstrates this philosophy through its commitment to mainstream education in the least restrictive environment and in its procedural and substantive provisions regarding the role of parents in the identification of needs and in the delivery of key special education and related services.

From their beginnings to the present day, major service programs—including developmental disabilities services,[15] Medicaid,[16] special education under IDEA, and VR[17]—have contained civil rights protections for those receiving services. These provisions have been strengthened and clarified throughout the 1990s. Specific provisions embodying our commitment to civil rights in these service programs have included appeal and other due process procedures for impartial review of agency or program decisions; requirements that individualized case services be provided pursuant to plans of service, in the nature of contracts jointly developed and agreed to by the service-provider agency and the individual or family receiving services; requirements that key program information be effectively communicated to the service recipient, including in alternative formats where necessary; and requirements for when and how the need for AT must be taken into account in the eligibility-determination, needs-assessment, and service-planning phases of involvement.

CONSUMER PARTICIPATION

As these due process, informed consent, and related procedural requirements indicate, consumer involvement, based on notions of empowerment and self-determination, has also been a key feature of statutes adopted or substantially amended during the 1990s. These principles are also evident in the overall structure and governance of these programs (e.g., the establishment of

rehabilitation advisory committees, state independent living councils, state developmental disabilities planning councils, and similar entities) to guide state and local agencies in the administration of the programs. Additionally, on the program-planning and regulatory-development levels, the commitment is evident in the methods adopted by such federal agencies as the Access Board and the FCC for developing guidelines to implement the requirements of Section 255 of the Telecommunications Act and Section 508 of the Workforce Investment Act. On both occasions, a government-industry-consumer committee was created (i.e., the Telecommunications Access Advisory Committee [TAAC] in the one case, the Electronic and Information Technology Access Advisory Committee [EITAAC] in the other).

ADVOCACY AND SYSTEMS CHANGE

Recognizing that the direct effects of many programs and expenditures can be magnified by long-term systems-change, many of the legislative enactments of the 1990s have included this concept among the goals and resources they provide. Illustrative of this feature of contemporary policy are the systems-change strategies and options contained in the Assistive Technology Act of 1998[18] (formerly the Technology-related Assistance for Individuals with Disabilities Act [the Tech Act]) Amendments of 1994.[19] State-based projects funded under Title I of the Act have been given the task of obtaining a greater visibility for, and focus on, AT in the work of a variety of agencies and programs in their states.

Systems-change, often expressed in terms of removal of barriers to employment, to education, to accessing other services, or to the acquisition of AT, is also a prominent feature of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA),[20] which endeavors to reduce key work disincentives in the Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) programs. TWWIIA is aimed at changing the health insurance system. Because recipients of benefits under these programs typically become ineligible for cash benefits after entering or returning to work, the linkage between cash benefits and Medicaid or Medicare health insurance coverage under these programs has often left those who return to work

uninsured when, as is all too frequently the case, they cannot obtain adequate health coverage through their employers. To help remedy this serious disincentive, TWWIIA extends to a total of about eight years the time during which Medicare recipients can continue to be covered under this insurance program and broadens the options available to the states for changing their Medicaid systems by allowing TWWIIA work-returnees to retain health insurance benefits under this program as well.

Most recently, the Bush Administration, although not embracing traditional systems-change terminology, has undertaken a multiagency study of a variety of barriers to access and participation in the programs operated by and in the laws governing more than a half dozen major federal agencies. This self-evaluation effort, undertaken as part of the Administration's *Olmstead* initiative and conducted pursuant to an Executive Order issued in June 2001,[21] resulted in the preparation of a preliminary report and findings by the Department of Health and Human Services (HHS) on December 26, 2001.[22]

Closely related to systems-change is advocacy. Legislation of the past decade often has provided advocacy resources for use both on behalf of and by individuals and for use in bringing about broad-based legal or institutional reform. Thus, such statutes as IDEA include technical assistance resources for training parents in understanding the special education system and in fully benefiting from the rights and services the law offers. Technical assistance to people with disabilities, governmental entities, and business is also a key component of the ADA and represents a significant element of the Department of Justice's (DOJ's) implementation of that statute.

Advocacy assistance has not been confined to education and training or to the provision of information about the law; it has also included creation of individualized legal advice and assistance resources, mainly through the protection and advocacy (P&A) system, to assist individuals not only in understanding but also in securing their rights. Such resources exist in the VR system, in the developmental disabilities program, and under the TWWIIA.

RESEARCH

Recognizing the technological, legal, economic, and social complexities associated with many of the issues faced by Americans with disabilities, Congresses and Administrations of both parties have placed a high priority on research. Conducted mainly through the National Institute on Disability and Rehabilitation Research (NIDRR)—also through a number of other agencies and programs under the auspices of agencies ranging from the Department of Commerce, the Department of Veterans Affairs, and the National Science Foundation—this research effort has featured the creation and support of a number of specialized rehabilitation engineering research centers (RERC) and rehabilitation research and training centers (RRTC). These include centers devoted to specific kinds of technology (e.g., telecommunications access, augmentative communications, or wheeled mobility) and centers concerned with specific issues or groups (e.g., older persons or children or technology transfer).

THE NATIONAL COUNCIL ON DISABILITY

NCD has been an active partner and catalyst for change in the public and private sectors over the past years, from its role in conceptualizing and building consensus and momentum around the passage of the ADA to its Tech Watch and other subject-specific watch committees that seek to identify access problems before they become acute and reach out to government and the private sector in an effort to foster timely dialog aimed at resolving problems to its recent work in developing consensus recommendations around education program monitoring[23] and description and elimination of the discrimination faced by persons with mental illness.[24]

As an oversight agency without legal power to direct the actions of others, NCD's impact stems from the cogency of its arguments and the depth of its commitment. Most recently, NCD has published a series of five civil rights monitoring reports addressing in detail the implementation of the ADA, IDEA, the Air Carrier Access Act, the Fair Housing Amendments Act, and Section 508 of the Rehabilitation Act.[25] Growing out of findings and recommendations from its 1996

disability summit,[26] these reports have cataloged impressive achievements in the protection of civil rights, but, as will be discussed, they have also uncovered serious and recurrent problems.

ENFORCEMENT

Taken individually and as a whole, these reports show that enforcement of disability civil rights statutes and of civil rights provisions of the laws creating service programs has fallen far short of what is minimally necessary to make these laws effective. Whereas the specifics differ from statute to statute and from enforcement agency to enforcement agency, some of the chronic problems disclosed are lack of resources devoted to enforcement; failure of agency leadership to identify enforcement as a high priority; lack of clear enforcement goals or of accountability for failure to meet such goals as do exist; absence of pattern and practices reviews by oversight agencies; poor coordination between and among agencies with overlapping or dual jurisdiction; lengthy backlogs and delays in civil rights complaint processing; failure to give the disability community reason to believe that consistent and meaningful redress for real grievances is available under law; and inconsistent involvement by people with disabilities in articulating priorities and providing advice on implementation.

NCD believes that without credible sanctions, achievement of progress in civil rights under law becomes all the more slow and difficult. As detailed later in this report, the stakes on effective federal enforcement have grown higher in the past year because a series of U.S. Supreme Court decisions has significantly narrowed the opportunities available for individuals with disabilities to pursue their rights by private lawsuits. These decisions include limiting the range of people who meet the definition of "qualified individual with a disability" for purposes of coverage under the employment discrimination provisions of the law; barring many suits by individuals against states for violation of most disability civil rights laws; and restricting the availability of fees to attorneys who represent individuals with disabilities in many civil rights settings.

THE NEW FREEDOM INITIATIVE

Another development in disability policy during the past year was the issuance in February of President Bush's New Freedom Initiative (NFI), reflecting the president's support for equality of opportunity and full participation in society for Americans with disabilities. The NFI includes several innovative approaches to the achievement of these goals. NCD believes that in the years ahead, through refinement and implementation, whether dealing with existing laws or with new legislative proposals, enforcement will remain key to achieving NFI's objectives and outcomes.

In charting new directions and seeking new ways to harness the energies and values of our society, the Administration and Congress can make all our laws meaningful by enforcing them with fairness and vigor, thereby bringing closer the day when not merely the laws but the values they enshrine become axiomatic in our daily lives and shared experience.

CONCLUSION

In the pages that follow, NCD continues its annual practice of reviewing policy developments from the preceding year and offering constructive, forward-looking recommendations in areas of greatest concern. NCD comes to its task this year with a sober awareness of the many new complexities, issues, demands, and preoccupations that lawmakers and members of the executive branch face. It does so also with the realization that the new policy initiatives and programmatic directions charted by the Administration and Congress will have profound and irreversible effects on the lives of all our citizens for many years to come.

In pursuing these new directions, we know society can no longer afford to consider so-called "disability issues" in isolation from the broader dimensions of policy and practice. Whether involving education, employment, health, or technology, the decisions we make about these subjects for the mainstream will affect all of us and cannot be made without full awareness of our indissolubility and oneness as a nation. Nor can decisions about disability policy be made in a

vacuum or on a clean slate. The context for these decisions and the options available to us are defined by what has gone before, and only through careful attention to the strengths and weaknesses of that record can we hope to build on our successes, avoid repetition of failures, and escape confusion and chaos. With attention to the past and confidence in the future, the potential of our values, our resources, our technology, and certainly our people is unlimited.

Chapter 1
Disability Statistics and Research

1. CENSUS 2000

NCD's 1999-2000 progress report expressed and documented grave concerns over the accuracy and reliability of widely disseminated information about employment rates among people with disabilities.[27] Our concern was that data developed from the latest Current Population Survey (CPS) questionnaire could lead to ineffective or even dangerous public policy decisions. The concern was based on a federal consensus that certain CPS items are not adequately designed to elicit accurate and reliable information from people with disabilities. So, recognizing the problems associated with the use of CPS data to assess employment rates, the Presidential Task Force on Employment of Adults with Disabilities (PTFEAD) was tasked to develop more accurate and reliable methods for determining the employment status of people with disabilities. This work is expected to be completed by July 2002—PTFEAD's sunset date—and is being conducted through the Bureau of Labor Statistics.

But even as recognition of the deficits in our current data is confirmed by further research,[28] repetition and dissemination of these data continue, much of that dissemination carried out with federal support. The danger of the situation is not merely in the proliferation of questionable findings, but in the effect of those findings on policy. For example, based in part on the conclusion that employment rates among people with disabilities have decreased during the 1990s, as the CPS data suggest, some researchers have inferred that the ADA, enacted into law in 1990, must be irrelevant or even a hindrance to the employment of Americans with disabilities.

As Congress and the courts grapple with key employment policy and civil rights issues, our deliberations must be guided by accurate and timely information. Whatever one believes about the wisdom of the ADA, the reliability of information is indispensable in evaluating its effects.

The Federal Government should not encourage or support the dissemination of employment data until a methodology for assessing employment rates among people with disabilities that is acceptable to leading researchers and demographers in the field and credible to persons with disabilities can be developed. This methodology, including proposed questionnaires or other data collection instruments, should then be validated through field testing before being put into widespread use.

Perhaps some researchers have embraced the CPS data and have been prepared to draw conclusions from it because it filled a vacuum. In the absence of other, more widely accepted, data and given the need for policy inputs, use of these data was convenient. But now, with the possibilities of a reliable methodology close at hand and with the Bureau of Labor Statistics findings expected soon, moving to the next stage of public policy development in this area should be possible and relying on questionable data simply because we have nothing better to fill the vacuum should no longer be necessary.

The issue here is not federal censorship but sponsorship. Although people have every right to use whatever data sources they choose, the government has an obligation to ensure that the information dissemination it supports, and the policy inputs it thereby generates, are as reliable as possible. To that end, when the Bureau of Labor Statistics offers a new methodology for the collection of employment data, NIDRR should convene a panel of demographers, labor economists, other appropriate researchers and policymakers, along with persons with disabilities, to review the proposed methodology for accuracy and reliability. NIDRR should also work closely with the Census Bureau, the Department of Labor's Office of Disability Employment Policy, and such other agencies as may be appropriate to carry out the field testing of all instruments suggested above.

A moratorium on federal support for the dissemination or federally funded use of unreliable disability employment data may admittedly cause some problems, but with better data collection

techniques imminent, such inconveniences are greatly outweighed by the harm that results from the continued infusion of erroneous information into the public policy pipeline.

2. RESEARCH

NCD continues to urge a broad review of all disability statistics and data collection strategies and of related disability research priorities and resources. Today, with evidence-based policymaking becoming progressively more central to governmental decisionmaking, reliable and accurate statistical information and research data are more important than ever in a wide range of policy contexts.

As the need for accurate and timely data grows, the complexities associated with collecting and analyzing it are also mounting. Even the most basic information, such as how many Americans there are with disabilities, has become steadily more difficult to collect or interpret. Four reasons for this difficulty exist. First, various statutes define disability differently. Given the differing purposes of various statutes, their yielding divergent estimates of the number of Americans with disabilities is not surprising.

The question whether disability is ultimately a functional, a social, or a legal concept is beyond the scope of this report, but from all these standpoints, the differing definitions and varying purposes underlying various statutes and programs enormously complicate the research, data collection, and policymaking processes. For example, the criteria by which a person meets the definition of disability under the ADA for purposes of protection from employment discrimination or the standards determining eligibility under the Social Security Act for SSDI or the test for whether someone can claim the impairment-related work expenses tax deduction are all quite different. Our notions of the size and the needs of the disability population will be greatly influenced by which of these definitions and by which functional measures we use.

A second and related reason why valid and reliable disability statistics and research findings are more difficult to collect is that even given the same statutory definition of disability, different agencies collect data in very different ways. The CPS illustrates this point. Given the same informational objective, and with the same statutes borne in mind, the Census Bureau has modified its questions in the 2000 census, and different formulations of the questions will necessarily bring different results. Any forthcoming new definition of disability, work-ability, or similar concepts will of course initially contribute to this problem by creating yet another database, but, in the long run, introduction of viable definitions of such terms will offer the opportunity for creation of baseline data that, coupled with the use of standardized techniques of administration, will yield truly comparable findings over time.

The third reason for difficulties arises from a very positive source, namely, the increasing role of assistive technology in the lives of Americans with disabilities. Because of technology, traditional definitions of when and whether a major life activity or function is "substantially limited" have become far more difficult to determine and far less universal. For example, impairments of mobility (often measured by the ability to move certain distances independently) or impairments of vision (conventionally assessed by ability to read standard print) are today, thanks to technology, not nearly so easy to assess as once they were. Today, the individual who cannot walk may still be able to get around with the assistance of a mobility device, and the individual who cannot see the newspaper may nevertheless be able to read it through the use of optical scanners. When asked if they are limited in the major life functions of reading or moving around, do the users of such technology answer in the affirmative? Likewise, if people whose use of technology allows them to work are asked whether they have a work disability, what will they say, and what should they say? Similarly, how many people who sincerely and reluctantly believe themselves unable to work by reason of a disability could in fact do so if they had access to appropriate technology or more accessible work environments? What answer should these people give, and what answer do they give? Does their legal status (that is, whether they meet the legal test for disability), their functional limitation, or their lack of access to appropriate technology and properly designed environments account for their lack of work?

The fourth and final reason for difficulty in the collection of valid and reliable employment or other data about Americans with disabilities arises from a series of Supreme Court decisions over the past three years that raise the potential for dramatically narrowing the legal standards for who is a person with a disability. These decisions, discussed later in this report, essentially hold that in determining whether someone qualifies as an individual with a disability so as to be covered by Title I (employment) of the ADA, certain mitigating measures, including at least medications and eyeglasses, must be taken into account. Moreover, in both the employment and public accommodations contexts, the Court has made clear that this determination must be made on an individual, case-by-case basis.

These decisions inordinately complicate any assessment of who the law considers to be a person with a disability and how Congress should define those whose lives legislation is designed to affect. But from the research standpoint, these decisions also play havoc with the questionnaires and other research techniques and the self-reporting data-collection strategies we use.

For all these reasons, the time is right and the need urgent for a comprehensive reassessment of all disability statistics and all data-gathering techniques. Under the authority of Congress, the Interagency Committee on Statistical Policy, in conjunction with NIDRR and NCD, should undertake this coordinated, comprehensive, high-level review.

Chapter 2
Civil Rights

I. THE ADA

a. CONTINUING ATTACKS

In July 2001, celebrations around the country were held to mark the 11th anniversary of the ADA. These celebrations, which have become an annual occasion for assessing progress and identifying barriers, hailed the many gains for people with disabilities over the past decade. But although proudly and gratefully recalling the many gains that have been made under the ADA, these annual events also provide an occasion for facing sober realities and for confronting the existence of many remaining, and some new, barriers.

This year, ominous new barriers were a topic of intense attention and grave concern. Efforts in Congress, such as the proposed ADA Notification Act,[29] would require individuals with disabilities seeking to file suit against "public accommodations" or "commercial facilities" under Title III of the ADA to give 90 days advance notice of their intention to do so. This requirement is not imposed on any other litigants seeking to avail themselves of protections or rights under federal law.

As discussed in last year's NCD progress report,[30] such proposals as the ADA Notification Act continue to sow fear among Americans with disabilities and to consume the time and energy of many advocates. To help allay deep-seated community concerns, *NCD recommends that the Administration and Congress put on record its unequivocal opposition to any weakening amendments to the ADA, especially amendments that treat the ADA in particular or civil rights laws in general in isolation from the rest of civil legislation in our nation.*

b. OTHER THREATS

Other new and disheartening threats to the ADA were also on the minds of this year's celebrants. Arising largely from judicial interpretations of the law, these new barriers to enforcement severely restrict the ability of private citizens to vindicate their civil rights in the courts.

By way of background to this year's decisions, which, in toto, continue and accelerate the process of closing the courts to civil rights claims by citizens with disabilities, the line of relevant decisions must be followed back to 1999. Then the Supreme Court ruled in the so-called *Sutton trilogy* of cases[31] that for purposes of the right to bring suit for employment discrimination under Title I of the ADA, the determination of whether a person is a "qualified individual with a disability" (in other words, whether an individual is covered by the law) needs to be made after various "mitigating" factors and measures have been taken into account. This ruling meant that many persons who previously would have considered themselves to have a disability and been commonly regarded as such were barred from bringing suit under the ADA because, with the application of such mitigating measures as the eyeglasses in *Sutton* or the blood pressure medication in *Murphy*, they no longer experienced "substantial limitation" of any pertinent major life activity, including the ability to work.

Following on the heels of this restriction in who has the right to sue, additional limitations have now been placed on whom discrimination suits can be brought against. The Supreme Court ruled in February 2001, in the *Garrett* case,[32] that ADA Title I employment suits claiming money damages cannot be brought against state governments, because the 11th Amendment to the Constitution bars suits against sovereign entities (which states are) without their consent.

Traditionally, even where a state has not consented to be sued, the 14th Amendment has overridden their immunity from suit in the civil rights area. This may remain so in connection with racial or gender discrimination, but may not be the case with disability-based discrimination. According to the Court in *Garrett*, the conditions established by the Constitution for federal legislation overriding state sovereign immunity have not been met by the ADA.

Whether Congress can revise the law to meet the standard by making more extensive findings of systematic and pervasive discrimination against people with disabilities by state governments remains uncertain. Given certain statements in the opinion suggesting that disability discrimination can in certain instances be "rational," and given the extensive evidence of pervasive discrimination that Congress already collected and cited in the ADA findings section and in its legislative history, considerable fear exists that the Supreme Court could hold that Congress lacks constitutional authority for overturning the *Garrett* ruling.

Other troubling uncertainties also surround the implications of these decisions. For instance, whether the *Sutton* decision and its companion *Murphy* decision will be extended to suits under Title II or Title III of the ADA remains uncertain. If they are, then the ability of individuals to contest alleged discrimination in the provision or denial of public services or public accommodations will likewise be substantially limited.

Similarly, critical unanswered questions attach to the more recent *Garrett* decision. Here again, the key issues relate to whether the decision will be extended. If states are immune from suit for money damages for employment discrimination, will they also be immune from such suits in connection with alleged denial of public services or access to public programs under Title II? To be sure, such decisions as the Court's 1999 ruling in *Olmstead v. L. C.*,[33] though predating the *Garrett* decision, have upheld the right of institutionalized people with disabilities to bring suit under Title II, and many suits under Title II, including *Olmstead*, seek outcomes that do not involve money damages. On the one hand, to hold that the 11th Amendment bars suits against states for injunctive relief or other nonmonetary relief, the Supreme Court would probably have to overrule its historic *Ex Parte Young* precedent, which has stood for nearly a century.[34] On the other hand, without being overruled, *Young* has been significantly limited by a variety of lower-court holdings in recent years, to the point where, for it to apply, suits must seek only prospective relief, must be brought not against the state but against named state officials, and must avoid a number of other highly technical pitfalls.[35]

It does not appear that *Garrett* bars suits against local governments, as distinguished from states. *Garrett* also does not detract from the Federal Government's ability to pursue Title I cases.

c. MIXED RESULTS

Last year's report noted uneven results in the implementation of the ADA. For example, whereas it noted appreciatively that city streets in most places are more accessible than ever before, NCD's progress report also observed that public transportation in many localities and regions remains inaccessible, unreliable, inconvenient, or untimely. While this pattern remains the case, NCD is encouraged by the transportation initiatives embodied in the president's New Freedom Initiative and by the approach taken to demonstration projects in the transportation area. These efforts are discussed in chapter 10.

Because of the accessibility of growing numbers of streets and sidewalks and because of the increasing incorporation of ramps and other environmental accessibility features into the design of public and commercial buildings, the number of people with mobility disabilities who now have entry to more buildings continues to grow. But as noted last year, more needs to be done. Some of these needs continue to exist in the realm of physical access. Others involve parallel access issues of concern to people with a variety of disabilities.

While we have by no means achieved universal physical access, as the law contemplates, the pressing issues of access for people with sensory disabilities and people with cognitive disabilities must also be addressed with vigor and focus. For these citizens, the access issues are not about their literal ability to enter the building but about their ability to locate the goods, services, facilities, or information that they want. These matters too will be discussed in greater depth later in this report.

Last year's report indicated that although the ADA covers Americans with cognitive and mental disabilities just as it does those with physical or sensory ones, these citizens continue to fight for

access to the programs offered by both public and private entities. Citizens with cognitive and mental disabilities face stereotypes and fears of a unique and persistent nature, the overcoming of which involves sustained and coordinated efforts in public education and law enforcement that include the efforts and resources of both the legal and public health sectors.

But across the spectrum of agencies and laws, and in connection with all disabilities, enforcement presents troubling and pervasive issues. These enforcement problems have been extensively documented. In June 2000, NCD issued its report *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act*,[36] which analyzed ADA enforcement efforts of the Department of Justice (DOJ), the Department of Transportation (DOT), the Equal Employment Opportunity Commission (EEOC), and the Federal Communications Commission (FCC).

Although recognizing the initiatives and positive actions of these agencies, NCD's 1999-2000 annual report also identified significant shortcomings in enforcement. These shortcomings included the lack of any coherent, unified, and comprehensive national enforcement strategy as a major weakness. The report found that enforcement efforts have been shaped largely by an approach based on case-by-case complaint handling rather than compliance monitoring and follow-up technical assistance.

Our research revealed that agencies, to varying degrees, have been hesitant to exercise leadership in litigating difficult or controversial cases or even in referring cases to the DOJ for litigation. The efficiency of complaint handling has varied greatly across agencies and the complaint handling process has been slow even in the best-performing agencies, and fraught with unreasonably long delays in the worst.

Despite several funding increases in the past decade, the report found that no federal agency had an enforcement budget commensurate with the scope of its ADA responsibilities. Another significant finding was that agencies have provided few opportunities for input from people with disabilities in setting overall priorities for policy development and enforcement activities.

Accordingly, NCD recommended that the DOJ assert strong leadership in bringing together the cognizant federal enforcement and oversight agencies to develop a strategic vision and plan for ADA enforcement across the Federal Government, including a well-coordinated litigation strategy. We recommended that all the agencies must look at ways to focus their enforcement resources on means to increase the consumer-responsiveness of key operations, such as complaint handling. We argued that all these actions should be undertaken with appropriate input from and collaboration by people with disabilities.

On balance, most of these recommendations remain to be acted on. With the advent of a new Administration, initially faced with the task of putting personnel, procedures, and policies in place and more recently faced with national security concerns of an unforeseeable nature, this inaction is certainly somewhat more understandable than might otherwise be the case. Nevertheless, we believe it important to emphasize that the DOJ has an uneven history of acting decisively to promote inclusion and accessibility for Americans with disabilities under the ADA.[37]

As we did in 2000, NCD once again commends the DOJ for intervening to help protect the integrity of the ADA and to defend it from the onslaught of lawsuits attacking the very basis of the law. Among the most notable instances over the past two years, the DOJ intervened in a court case to establish insurance as a public accommodation under Title III and to blunt efforts aimed at securing a judicial determination that Title III did not apply to goods and services made available to the public over the Internet, filing important amicus briefs in cases heard by several U.S. Courts of Appeal.[38] Additionally, the DOJ filed an amicus brief in the *Nored* case[39] challenging a Tennessee statute that prohibits people with "any apparent mental disorder," even the most minor, from occupying positions as public safety dispatchers.

Along with commending the DOJ for its efforts to establish constructive policy positions through the courts, NCD also urged the DOJ to make use of the variety of tools at its disposal (including regulations, subregulatory guidances, and technical assistance documents) to take a leadership

role on policy issues in Title II and Title III enforcement and to help covered entities understand and comply with their obligations under the law in emerging areas, such as e-government and the Internet, that have not been highlighted in enforcement efforts or technical assistance releases to date.

Needless to say, the types of arguments the DOJ can make in court and the kinds of enforcement and technical assistance activities it can undertake depend in large part on the issues involved. In this connection, one crucial difference between the *Sutton* trilogy and the *Garrett* cases must be noted: Whereas *Sutton* is based on statutory interpretation, the *Garrett* decision is predicated on the Constitution. Nevertheless, both decisions present major issues for the DOJ to resolve and opportunities for the DOJ to act. In addition, both decisions also present major issues for EEOC to act on.

The first question to be asked about the DOJ's responses to these decisions is whether the department believes these cases to have been correctly decided. Consistent with fidelity to and respect for the decisions of the high court, various well-established strategies for reversing or limiting these decisions exist, but the DOJ must believe that the decisions represent a misconstrual of statutory meaning or constitutional principles. The *Sutton* trilogy decisions, because they rely on interpretation of the ADA, can readily be overturned or modified by congressional amendment of the law. Numerous precedents, such as the Civil Rights Restoration Act of 1991, exist for such congressional response in the civil rights arena over the past 15 years. Leadership by the department would be invaluable in seeking to clarify, for example, that mitigating measures do not include submission to involuntary or potentially harmful medical treatment and that such measures do not include the use of AT. If the DOJ were not prepared to go so far as recommending overturning of the postmitigation assessment of major life-activity limitation, clarification of what will and will not constitute applicable mitigation under the law would allow the postmitigation standard to continue in effect, while ensuring that workers will not be forced to submit to coercive interventions in their health and private lives as a condition for pursuing their aspirations to work.

With *Garrett*, the constitutional basis for the decision makes the task of modifying its effects far more daunting. In *Garrett*, the state of Alabama successfully argued that the ADA does not meet the criteria established by the 14th Amendment for enactment by Congress of civil rights laws that override states' 11th Amendment sovereign immunity from suits. In reaching its decision in the case, the court found the following: (1) Congress lacked (or, in the findings section of the ADA, failed to articulate) sufficient evidence of systematic discrimination and denial of equal protection to people with disabilities by the states to justify the abrogation of 11th Amendment immunity; and (2) even if the evidence of systematic discrimination were sufficient to justify congressional action to set aside states' sovereign immunity, the requirements of the ADA, including the provision of reasonable accommodations, go so far beyond what would constitute a mere ban on discrimination as to constitute a disproportionate and excessive response on Congress's part to the problem the statute sought to address.

It is interesting that the DOJ itself filed briefs supporting the constitutionality of the ADA and urging the Supreme Court to hold the ADA's express abrogation of states' 11th Amendment immunity to be a proper exercise of Congress' power to enforce the equal protection clause of the 14th Amendment.[40]

In last year's progress report, NCD forecast that "the court's decision will have a crucial bearing on the future of disability rights." If anything, that was an understatement. Pending further decisions, a number of key issues, bearing on all civil rights statutes and presumably even on access to services provided under federal-state partnerships, hang in the balance. In addition to those already noted in subsection b, the key issues now in play are whether the Court's reasoning in *Garrett* applies to other federal disability rights statutes, such as Section 504 of the Rehabilitation Act,[41] and whether and how states can waive or be deemed to have waived their sovereign immunity from private lawsuits.

These questions will be taken up later in this chapter when we discuss recent court decisions that do not directly involve the ADA but may have a profound and adverse effect upon it. For the

moment, in light of the continuing uncertainties and in view of the fears of many persons with disabilities that their hard-won civil rights face dramatic and severe erosion, *NCD recommends that the DOJ develop and assert clear and unambiguous views on these points, both for presentation to Congress and, subject to the inevitable factual variations in each case, for use in the courts as circumstances warrant.*

2. HATE CRIMES

In last year's report, NCD recommended that Congress hold hearings to extend federal hate crimes legislation to cover a variety of population groups, including persons with disabilities. NCD reiterates its recommendation that such legislation be adopted in 2002.

Recent months have provided the most painful reminders of what hate and prejudice can do. As our nation struggles to accommodate its values of respect and equality to an era of personal fear for many and security concerns for all, decisively and expansively asserting, in law as in practice, the enduring values that we hold becomes more important than ever. At this time, too, ensuring that all Americans are recognized and made to feel welcome as full members of our society is vital.

For Americans with disabilities, this means freedom from, and legal protection against, the extreme form of discrimination represented by bias crimes. Whether such crimes are predicated on malice, an opportunistic belief that people with disabilities are less likely to resist, resentment at the civil rights demands of these citizens, or other causes, society must make clear, through the unqualified pronouncement of federal law, that our disapproval of hate crimes is backed up by meaningful sanctions and deterrence.

Accordingly, *NCD strongly recommends that Congress enact appropriate federal hate crimes legislation during its 2002 session.*

In last year's status report, NCD also recommended that Congress increase appropriations for preventing and responding to alleged violations involving certain federally protected activities. Where manifestations of hate arise from or are directed against people in response to their pursuit of or exercise of federally protected rights, society's responsibility is all the greater. Because retaliation in any form places a heavy burden on the vindication of all rights and on the exercise of the responsibilities of citizenship, resources must be identified and strengthened for ensuring that the requisite vigilance, investigation, and follow-up are available and used.

In its 1999-2000 annual report, NCD commended the proactive efforts of the DOJ'S Bureau of Justice Assistance (BJA) to raise awareness at all levels of government regarding hate- and bias-related crimes. *NCD recommends that these efforts, under the National Hate Crimes Training Initiative, continue. But NCD also recommends that the curriculum be reviewed to ensure that issues bearing specifically on hate crimes against persons with disabilities are fully incorporated and adequately addressed in all videos, manuals, in-person trainings, and other materials and efforts. Specifically, NCD recommends that BJA ensure that the role of bias in opportunistic crimes against persons with disabilities be fully appreciated by law enforcement personnel; that crimes committed by caregivers against persons with disabilities be recognized as bias crimes where warranted; that the difficulties faced by many people with disabilities in bringing their experiences of victimization to the attention of law enforcement be recognized; and that government agencies and officials at all levels make special efforts to ensure that people with disabilities who have been the victims of hate crimes are accorded every opportunity to participate effectively in the legal process to secure redress and protection.*

NCD also recommends that training materials and official practices identify and candidly address what may best be described as the secondary consequences of bias. If a police department or public prosecutor declines to pursue charges against a defendant out of a belief that a witness or victim with a disability may not be regarded as a credible witness (as is widely reported to happen in cases of persons who are blind and therefore cannot make visual identifications of suspects), or if a prosecutor declines to call a person with a mobility disability

as a witness because the courthouse is inaccessible or a sign-language interpreter is unavailable, then the individual with a disability has been doubly victimized: once by the alleged hate crime, then by the inability of the justice system to demonstrate the necessary flexibility and responsiveness.

Because they result in decisions being made that affect people's lives on the basis of factors that deny the individuality and uniqueness of each person, stereotypes are as harmful as bias, even when motivated by manifestly protective instincts. Unless hate crimes are recognized for what they are and dealt with effectively through training and oversight, any attempt to deal with them that does not take the institutional response into account is unlikely to achieve the level of success desired. Accordingly, *NCD recommends that BJA take all possible measures to identify these issues and to ensure their proper prioritization in all hate crime–related training efforts.*

3. GENETIC DISCRIMINATION

A year ago, NCD recommended that legislation barring discrimination by health insurers or employers based on genetic information be introduced and acted on by the 107th Congress. NCD believes that recent developments have made the case for legislation barring genetic discrimination more pressing than ever.[42]

As a backdrop to the discussion of the specific provisions that such legislation should contain, *NCD recommends that the Office of Management and Budget (OMB) or the Office of Personnel Management (OPM) undertake an assessment of the impact of Executive Order 13145, issued by the previous Administration, which barred federal agencies from making use of genetic testing in hiring and promotion decisions and further required adherence to all applicable state and federal confidentiality provisions in those rare instances where a federal employer needed to obtain genetic information about a present or prospective employee.* The assessment recommended here should seek to evaluate the extent of compliance among federal agency employers, the administrative viability of the order's provisions in light of other legal and

practical requirements bearing on the public sector employment relationship, and the impact, if any, of the order on documented short-term or actuarially anticipated long-term costs of providing health insurance to federal workers and their dependents.

Based on the findings of this assessment, which should be completed within the life of the 107th Congress (but which should not serve as grounds for delaying reform legislation that may in the interim be considered by Congress), the Administration should propose legislation that builds on the lessons learned in the federal sector but that applies to all employers and all providers of health insurance coverage.

As suggested, new urgency has been lent to the subject of genetic screening for employment by the rapid growth of interest in genetic testing and by scientific discoveries, associated with completion of the human genome mapping project, that purport to link specific diseases with the presence, absence, or mutation of particular genes. Although no authoritative data have been found, all indications point to the increasing use of genetic screening by employers.

Leaving aside the likely sensationalistic nature of press coverage concerning these biomedical breakthroughs, many believe that creation or manipulation of genes in the laboratory or the test tube is a process that should be approached only with the gravest humility. Others believe that such technology represents a great opportunity for increasing longevity and enhancing the quality of life. For those who believe that genetic research holds the key to the conquering of disease and a better life for all, and alike for those who believe some or all contemporary genetic research to be an assault on the fundamental dignity of the human being, use of genetic information to condition the availability of employment or health insurance should be equally anathema.

From the standpoint of any strong opinions about the wisdom or the direction of genetic research, the conditioning of key decisions about people's lives on information concerning their genetic endowment should be a matter of the utmost concern. To those who regard biotech as scientifically promising and ethically sound, it must be apparent how the fear of genetic

discrimination can lead people to forgo testing and diagnosis and, in due course, limit the pool of available persons for participation in clinical trials. Likewise, to those who regard genetic research and testing as scientifically misguided or morally objectionable, the intolerability of allowing employers or HMOs to make decisions about people's lives based on such information must surely be equally apparent.

Some may argue that denying employers or health insurers the right to use genetic information in determining who to hire or who to insure will result in driving up insurance costs for all, ultimately reducing the availability of coverage in our nation. We have been able to discover no data to support this hypothesis. On the contrary, although also not demonstrated by statistical research, the opposite appears more likely, and it seems fair to propose that by allowing the collection and use of genetic data for employment or insurance purposes, we may create so much fear of genetic information among the populace at large that people will avoid or delay seeking medical care for all manner of symptoms and conditions until their illnesses are far more advanced and far more costly and destructive. Thus, whatever the impact of a ban on genetic testing for health insurance costs, failure to institute the necessary protections may well raise the overall costs of health care for our economy. Thus, to allow genetic testing unchecked in insurance and employment may represent not a savings, but a shifting of costs in all too many cases to the public sector as payer of last resort.

NCD endorses legislation imposing strict confidentiality requirements on the use of genetic information and authorizing monetary damages and other penalties for its misuse or unauthorized release. Yet, experience and legislative precedent may dictate recourse to a still higher standard in this area. Rather than simply impose restrictions on the use of information and penalties, however severe, on the misuse of information, we believe the better course is to prevent acquisition of the information in the first place, except in those cases where clear and compelling grounds exist for its provision. Accordingly, *NCD recommends that in most cases, and except where specific exceptions apply, employers and insurers should be barred from seeking or collecting genetic information. To prevent circumvention of this ban, employers and insurers*

should also be barred from making the waiver of genetic privacy rights a condition of employment or coverage.

If Congress is unable or unwilling to protect genetic privacy, it should at least clarify that discrimination in employment or insurance (including self-insured employer plans regulated under the Employee Retirement and Income Security Act of 1974 [ERISA]) based on genetic makeup or genetic predisposition is a form of disability discrimination, actionable under the ADA or other civil rights laws. The DOJ should take the lead in working with Congress to develop and support such legislation.

Without broad-based protection of genetic privacy, the freedom and opportunity that mark our nation may become conditioned by the identity of one's parents, in ways never imagined outside of science fiction until now, but ways that are all too imminent and real nonetheless. Truly, then, will the sins of the parents, and of their parents before them, be visited on the children.

4. VOTING ACCESSIBILITY

A year ago, NCD urged adoption of amendments to the Voting Accessibility for the Elderly and Handicapped Act.[43] These recommended amendments provided that all polling methods used in federal elections, including voter registration, be accessible to voters with disabilities and voters who are elderly.

The tense and uncertain weeks that followed last November's presidential election will never be forgotten by anyone who lived through them. Whereas the peaceful methods our nation used to resolve its succession crisis are surely a model to the world, the election and its aftermath also exposed significant shortcomings in our electoral procedures and technology. As important, last year's election served as the occasion for the United States Supreme Court to make clear in its *Bush v. Gore* decision that equal protection in the exercise of the franchise is a matter of central and national constitutional concern.

As anecdotes and surveys have made clear, many Americans with disabilities face obstacles in voting far greater than confusing instructions or malfunctioning machines. Some are able to vote only with difficulties that would be intolerable to other citizens or by forfeiting the fundamental protection of the secret ballot, and some are unable to vote at all, solely by reason of the interplay between their disabilities and the arrangements for voting we have thus far made. When an individual's local polling place, or any reasonably located polling place, is inaccessible to persons who use wheelchairs or who have other mobility disabilities, we place such citizens under access burdens that we would not allow if they were going out to buy a hamburger. It says little, or perhaps much, about our esteem for the right to vote that we have made better and more far-reaching arrangements for the accessibility of fast-food restaurants than we have for the places where Americans choose their leaders. Yet, throughout this country, the problem of inaccessible polling places remains vast.

Nor is the physical accessibility of the polling place or of the voting booth the only barrier. For citizens with visual or other disabilities that prevent them from reading the print instructions on voting machines or from independently knowing which lever to pull, which touch zone to tap, or which box to mark, the right to vote does not include the privilege of a secret ballot, and this despite the fact that technology exists and has been successfully used in several jurisdictions that would allow the independent casting of votes through the use of speech output in addition to print on the voting machine.

At the same time, the voting booth poses obstacles to persons with cognitive disabilities who need assistance in voting but whose access to available and sensitive assistance depends totally on chance.

Additionally, for those persons who, because of age-associated frailty or because of disability, cannot get to the polls to cast their votes in person, absentee ballot laws too often provide inadequate protections. Absentee ballots, as governed by a multiplicity of state laws, may be legally unavailable to persons who are actually present in the jurisdiction on election or primary

day or they may require a signature that an individual cannot render or an attestation or oath (from a person who needs physical assistance in marking the ballot) that no one else has filled it out. The absentee ballots may be provided only in print, requiring persons who are blind and who need to dictate their choices to someone else not only to again sacrifice their secret ballot but also, in cases in which one or another such oath is required, to potentially trade their right to vote for the dubious opportunity of committing perjury.

The barriers to citizenship do not end here. Voter guides and other instructional materials are rarely provided in alternative or accessible formats, and when they are it is generally by the grace of local election officials rather than through any sense of legal obligation.

Statistics assembled and presented to Congress by NCD in 2001 put the situation into dramatic profile.[44] A full one-third of persons with disabilities of voting age are not registered to vote. Even outreach to these voters under the Motor Voter Act has fallen short, judging for example from the fact that some 42 percent of persons receiving vocational rehabilitation services were never offered the opportunity to register. Some 81 percent of persons with significant visual impairments must sacrifice their right to privacy (a right taken for granted by everyone else) in order to vote by reason of the fact that they cannot independently read or enter the necessary information. Most striking of all, if Americans with disabilities were able to vote in the same proportions as their nondisabled fellow citizens, some 3.5 million more votes would have been cast in the November 2000 national elections.

Unless we are to adopt the notion that people with disabilities care less about the future of their country or about their civic duty than other citizens do, responsibility for this disparity must be laid squarely on the difficulties and barriers these disenfranchised citizens face in attempting to enter the civic mainstream.

Recent and pending federal litigation holds out some hope of reform, but the broad-based reform legislation currently under consideration by Congress is the key to improving or perpetuating this

unacceptable situation. In this connection, NCD made detailed recommendations to Congress concerning the Help America Vote Act of 2001,[45] which the House adopted and referred to the Senate in December.

A number of states have also enacted election reform legislation in the wake of last year's experience, but few if any of these state laws appear to address the unequal protection of the laws encountered by so many citizens with disabilities in their efforts to exercise the simple democratic right of voting. Faced with this evidence of state inability, or indifference, only Congress can act to ensure equal protection of the laws, as the Supreme Court boldly undertook to do last year.

As the 107th Congress returns to the consideration of federal election reform legislation in its second session, the Senate will initially be called on to adopt its version of voting reform and assistance legislation. Because the House has already adopted legislation, the subject cannot be considered de novo in that chamber. Nevertheless, through Senate action and the eventual work of the conference committee, *NCD recommends the passage of legislation that meets the concerns raised in our submissions to Congress and in our reports and studies.* It is essential that the eventual legislation provide direction, incentives, and flexibility to states in making federal elections accessible to people with disabilities, but the legislation must contain national standards that guarantee privacy, accessibility of voting facilities and election equipment, and accessibility of registration and voting procedures and of voter information to all persons with disabilities.

The legislation should further provide for culturally sensitive and appropriate assistance to voters with disabilities at the polls and in outreach to voters with disabilities, among other disenfranchised groups, to educate and assist these citizens and to ensure that they are able to register and vote with dignity. Appropriate technical assistance and training should be made available to poll workers, local elections officials, and others who have contact with voters with disabilities or who bear any measure of responsibility for the electoral process. Additionally, the law should provide for the involvement of representatives of the disability community in its

implementation and in the development of policies, oversight, and regulations under the law. Finally, the new law must provide for its enforcement and for the accountability of state and local officials for that enforcement.

5. CONGRESSIONAL ACCOUNTABILITY ACT

In its 1999-2000 annual report, NCD recommended that the Congressional Accountability Act (CAA) of 1995[46] be amended to make the provisions of Section 508 of the Rehabilitation Act applicable to all congressional "instrumentalities." On December 31, 2000, the Office of Compliance (the agency established by the CAA to administer the law's provisions and to report to Congress on changes that should be made in the law) issued its statutorily required biannual report. In that report, the office indicated that it was not yet in a position to recommend coverage of the congressional instrumentalities (namely, the General Accounting Office [GAO], the U.S. Government Printing Office [GPO], and the Library of Congress [LOC]) under Section 508. The office indicated that further experience and research were needed before such a coverage recommendation could be made.

On November 13, 2001, the Office of Compliance issued an interim report *recommending that the CAA be amended to make the provisions of Section 508 applicable to all congressional employing offices and specifically to the three congressional entities noted.*[47] *For the same reasons stated by the Office of Compliance in its interim report, NCD joins in this recommendation and commends the Office for the soundness of its analysis and conclusions.*

The interim report indicates that a number of key factors have changed during the past year. Most notably, the report cites the fact that regulations governing the operation of Section 508 and detailing its requirements have been put into effect for the executive branch and that the executive branch has been operating under these regulations since they came fully into force on June 25, 2001. Significantly, the executive branch has suffered no serious dislocation as a result of the implementation of these important new access provisions.

In addition, the office's interim report notes that one of the congressional instrumentalities, GPO, has undertaken voluntarily to comply with the Section 508 guidelines in its management of some 30 Web sites on behalf of executive branch agencies. Once again, the evidence from this voluntary compliance is favorable to Section 508. Application of the provisions of Section 508 to congressional employing offices and to the congressional instrumentalities is manifestly in the public interest and has been deemed feasible and cost-effective. Its application to the congressional instrumentalities would simplify the provision of access for all because it would create greater clarity and standardization regarding what is required and would facilitate the sharing by Congress of the many training and technical assistance resources that have been created under Section 508 in its implementation efforts. With these resources and the associated experience, and with the commitment given by the Office of Compliance to be of assistance in the implementation process, Congress should have no hesitation in adopting the recommended amendment to the CAA.

Accordingly, *NCD recommends that Congress enact the needed amendments to the CAA promptly and provide for the technical assistance and other resources necessary to ensure effective incorporation of the principles and provisions of Section 508 into the work of all congressional offices and entities without delay.*

6. OUTREACH TO DIVERSE CULTURAL GROUPS

As NCD noted in last year's report, a large segment of the population, particularly those from diverse racial, cultural, and ethnic communities, continue to be excluded from full participation in all aspects of American society. Years of model programs, technical assistance, and other federal initiatives have failed to adequately improve the status of people with disabilities from diverse cultures.

Overall concerns include (1) unequal access to and benefits under the same federal laws that have seen at least some level of implementation for the larger disability community, and (2) the persistence of dual discrimination as a barrier to people with disabilities from diverse cultures.

America's diverse population requires us to make a conscious effort to ensure that the needs of all people are addressed. In this regard, NCD acknowledges the commitment to inclusion reflected in President Bush's New Freedom Initiative and the commitment of the Administration to educational reforms that reach all students, including those from minority and disadvantaged backgrounds and those with disabilities, and that promise the use of innovative strategies combining flexibility and accountability. Although expressed in different terms and, in many cases, with different implementation strategies, these new initiatives represent the continuation of a bipartisan commitment that has spanned administrations and congresses of all parties.

a. THINK TANK 2000 ON DIVERSE CULTURES

Congressional representatives, national civil and human rights leaders, people with disabilities, and people from diverse cultures participated in NCD's May 2000 Think Tank project to define a more inclusive public policy agenda pertaining to the needs of people from diverse cultures. The participants reached consensus on three areas for strategic action: (1) promote leadership development and include emerging leaders in public policy decisionmaking; (2) disseminate user-friendly and culturally sensitive information on rights and responsibilities; and (3) work to build and strengthen alliances with civil and human rights groups in the broader community.

NCD was asked to continue assisting with conversation around these issues and has continued to do so. A summary paper from the May 2000 workshop, *Carrying on the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures*, can be accessed on the NCD Web site.[48]

NCD recommends that these efforts continue and that the Administration and Congress undertake to participate in this process, to review the findings and recommendations of the Think Tank paper and follow-ups, and to work with emerging leaders of diverse cultural backgrounds from the disability community to continue refining its response to their needs and concerns within the framework of its overall outreach and reform efforts in education, housing, civil rights enforcement, and other contexts. To this end, NCD recommends that the Administration designate a liaison for this outreach.

b. PRESIDENT'S INITIATIVE ON ASIAN AMERICANS AND PACIFIC ISLANDERS

A 1999 Executive Order was aimed at increasing the participation of Asian Americans and Pacific Islanders in federal programs.[49] Subsequently, members were named to the Advisory Commission on Asian Americans and Pacific Islanders. The commission studied ways to increase public and private sector and community involvement in improving the health and well-being of Asian Americans and Pacific Islanders, increase their participation in federal programs in which they may be underserved, and foster research and data collection, including information on public health.

These outreach efforts elevated key issues of concern to these populations to a heightened level of visibility. *NCD recommends that the Administration follow up on the work of this commission, with a view to identifying and implementing recommendations and findings where appropriate, with particular attention to those findings and recommendations that illuminate the intersection between these groups and disability.*

In connection with such follow-up, NCD commends the Administration for its creation, under the auspices of the NFI, of the National Technical Assistance Center for Asian Americans and Pacific Islanders. NCD hopes and expects that the new center will be successful in addressing a broad range of issues and in reaching out to a broad spectrum of Asian Americans and people from Pacific Islander cultures.

c. NATURALIZATION AND RELATED IMMIGRATION ISSUES

In last year's annual report, NCD noted recent legislation allowing waiver of the usual oath of allegiance requirements for new citizens with disabilities who could not take or fully comprehend the oath. The report also discussed related field guidances issued by the Immigration and Naturalization Service (INS) to its field offices. The INS issued field guidance and policy modifications for naturalization processing and adjudication to its field adjudicators on April 7, 2000. The guidance was unclear, however, on how to accommodate applicants with severe disabilities with respect to the legal requirement that they understand the oath of allegiance.

Enactment of P.L. 106-488, amending the Immigration and Nationality Act, in November 2000 substantially remedied this problem. The new law provided a waiver of the oath of renunciation and allegiance for naturalization of aliens having certain disabilities.

NCD recommends that the INS ensure timely and effective processing of naturalization applications for applicants with disabilities. To that end, the Disability Rights Section of the Civil Rights Division of the DOJ, together with NCD and the INS, should undertake to conduct a comprehensive review to monitor the implementation of these recent statutory changes, with a view to assessing the success of INS's efforts to address long-standing problems with its naturalization process regarding access for people with disabilities and with a view to anticipating and proactively addressing issues that have an impact on the citizenship applications of these aspiring Americans.

In reiterating these recommendations, NCD is acutely aware of both the chronic resource limitations faced by the INS and the enormous new demands placed on that agency by our efforts to better track and regulate the entry and tenure of noncitizens in our nation. But precisely because we have come to understand as never before the value of American citizenship and the reasons so many people from all parts of the world aspire to it, the importance of ensuring that

general reforms do not overlook the needs of people with disabilities is likewise greater than it has ever been.

Current issues of concern to applicants with disabilities in the immigration and naturalization process, in normal times and in these, are not limited to those involving the oath. From access to immigration facilities, to access to written information, to assistance in the completion of forms, to the availability of sign-language interpreters (including for materials and interpreters in languages other than English), many subsisting and emerging concerns need to be addressed. As they relate to cultural diversity, and in their own right, these issues need to be addressed, and where problems are disclosed, they need to be dealt with by the Administration with the high priority that the values of citizenship confer on them.

d. UNDERSERVED AND UNSERVED DIVERSE COMMUNITIES

In October 2000, the Department of Education (ED) funded a competitive grant for the first national native American center, the American Indian Disability Technical Assistance Center (AIDTAC). Located in Montana, the center helps American Indians and Alaskan Natives with disabilities live integrated lives in their native communities. AIDTAC is committed to helping tribes build their capacity to develop and implement culturally appropriate laws and policies, crosscutting infrastructure, and direct program services. *NCD recommends that the ED evaluate these efforts with a view to determining their potential applicability to other communities in other settings and with a view to their refinement and incorporation into the NFI.*

e. ELIMINATION OF LANGUAGE BARRIERS TO FEDERAL PROGRAMS

On August 11, 2000, Executive Order 13166 was issued requiring that all federal programs using federal funds ensure that language barriers not prevent participation in or hinder benefit from these programs for non-English-speakers and people with limited English proficiency. The order was intended to ensure that people from diverse cultures with disabilities and their families could

take full advantage of federal laws, programs, and services by receiving understandable, culturally appropriate information about their rights and responsibilities under various federal laws.

NCD recommends that the Administration indicate its position with respect to the principles embodied in the Executive Order, and that if the Administration continues to subscribe to these principles and methods, it support the formation of an interagency team composed of representatives from the Departments of Education, Health and Human Services, Housing and Urban Development, Justice, and Labor, along with the EEOC, FCC, and Small Business Administration, to develop and implement appropriate outreach and training programs and to develop and provide the kinds of technical assistance necessary to make them effective. To facilitate such outreach and dissemination, NCD recommends that the interagency team recruit, train, and contract with a core group composed of people with disabilities from diverse cultural backgrounds and their family members to help (1) develop the written materials and programs that will be used for the trainings; (2) translate materials into many languages, including in accessible and alternative formats, with sensitivity to cultural appropriateness of terminology; and (3) sponsor or conduct the trainings once the appropriate materials are translated, field-tested on sample groups, and produced for dissemination in communities. NCD also recommends in this connection that Congress provide funding support to the federal partners and sponsors of the trainings or other incentives to partners in order to eliminate potential financial barriers to participation by team members of limited means.

f. CONTINUING RECOMMENDATIONS

In its December 1999 report *Lift Every Voice: Modernizing Disability Policies and Programs to Meet the Needs of a Diverse Nation*,[50] NCD made comprehensive recommendations for eliminating gaps in access experienced by persons from diverse cultures or who speak languages other than English. Ranging from employment to child care to access to governmental services

and information to diversification of human-services personnel and a host of other key areas, *Lift Every Voice* offers a blueprint for action and change that we believe remains viable and timely.

Although likely to grow more slowly as immigration procedures are reviewed and tightened, all indications continue to point to a steady increase in foreign-born and first-generation Americans among our native-born, naturalized, and legal-immigrant population. Just as the Administration has recently undertaken a multiagency review of access barriers in federal policy and law to the implementation of the *Olmstead* decision, *NCD also recommends that the Administration, with its* Lift Every Voice *report as a starting point, comprehensively address those barriers that are specific to people at the intersection of disability and cultural diversity.*

7. FURTHER CLOSING OF THE COURTHOUSE DOOR

a. SOVEREIGN IMMUNITY

Earlier, in section 1c of this chapter, we discussed the barriers to enforcement of civil rights for persons with disabilities posed by the Supreme Court's February 2001 *Garrett* decision. Although *Garrett* dealt with application of the 11th Amendment sovereign immunity doctrine to suits brought under the ADA and with the extent to which the 14th Amendment bears on that immunity, statutes other than the ADA and civil rights constituencies other than people with disabilities are affected by recent Court jurisprudence in this area. Including the *Kimmel* decision,[51] which barred private suits against states under the Age Discrimination in Employment Act (ADEA), the Supreme Court has applied the sovereign immunity doctrine to bar suits against states under a variety of federal laws.

In the wake of these decisions, attention has increasingly turned to the question of whether and how states can lose their sovereign immunity, particularly how they can waive their sovereign immunity and consent to be sued under federal laws purporting to authorize the right to sue. While the case law is inconclusive, some believe that under the spending clause of the

Constitution, states can be required to waive their immunity from suit as a condition for the receipt of federal funds. Under this theory, states would be required (or be deemed) to waive their immunity and consent to be sued under such statutes as the Rehabilitation Act, IDEA, or Medicaid, as a condition for receiving federal grants under these programs. Others take the view that such waivers would be compelled and therefore ineffective if not knowingly and voluntarily given.

Whatever the uncertainties surrounding congressional power in this area, individual states have the right to waive their immunity from suit. State law will determine how this can be so done—whether a statute is required or a gubernatorial executive order or waiver by the attorney general will do—but especially in states that already have their own human rights laws covering disability discrimination, the implications of consenting to suit under the ADA or other disability rights statutes would appear fairly small.

b. THE RIGHT TO COUNSEL

In section 1c of this chapter, we discussed the heightened responsibility of the Federal Government for enforcement of civil rights laws that results from judicial decisions restricting the access of private citizens to the courts. But the impact of the decisions discussed thus far, and even of the *Sandoval* decision discussed in subsection d of this chapter, may be outweighed by still another 2001 Supreme Court holding. In the *Buckhannon* case,[52] decided in March 2001, the Court significantly restricted the circumstances in which civil rights litigants can obtain lawyers' fees.

Previously, if a civil rights suit resulted in a significant change of policies or practices by the defendant, the plaintiff whose suit brought about these changes was entitled to an award of attorneys' fees under the "catalyst theory." The individual who was the catalyst for change was the "prevailing party" within the generally accepted meaning of the law, and prevailing parties are generally entitled to reasonable attorneys' fees. In *Buckhannon,* however, the Court held that

being the catalyst for change was not sufficient to make a plaintiff a "prevailing party" within the meaning of several laws. To be a prevailing party, one had to be awarded damages or some other specific relief from a court. Even a settlement between the parties that resulted in the payment of some money damages to the plaintiff will not do.

The *Buckhannon* decision is likely to have a devastating effect on the ability of individuals with disabilities to find legal counsel among the private bar. The limited resources of the protection and advocacy (P&A) system and of the pro bono sector of the private bar are unlikely to expand materially or be able to take up the slack. But *Buckhannon's* potential harm is not limited to this. Even from the standpoint of those who may believe that civil rights statutes have spawned excessive litigation, the decision bodes adverse consequences. Rather than seek to foster the ability of the judicial system to distinguish meritorious from unmeritorious cases, and rather than attempt to structure the rewards and punishments of litigation to reward cases of merit, the decision actually punishes those with serious and worthy claims because it denies attorneys' fees in those instances where defendants settle out of court, making the changes requested, out of a recognition that the plaintiff's position is legally sound. Even for those who believe that attorneys' fees contribute to unnecessary litigation, the goal should certainly be the establishment of a system that somehow makes distinctions on the basis of quality and significance.

Various theories have been advanced as to how *Buckhannon* will affect the legal strategies and professional ethics of both plaintiffs' and defendants' counsel. Although these remain largely speculative, one conclusion that seems beyond doubt is that the great difficulty individuals with disabilities already face in locating private counsel to pursue and defend their civil rights can only be multiplied exponentially. Even in highly meritorious cases, the odds of winning monetary damages or other relief from a court at the end of a long process are too remote and too delayed to make civil rights representation viable for most attorneys.

Taken together with these cases, and with the *West Side Mothers* case discussed in the next subsection, this jurisprudence practically leaves the Federal Government as the only entity with

the capabilities and resources to vindicate the civil rights of an increasing proportion of America's citizens with disabilities. Unless the government is prepared to fill the vacuum created by these decisions, it should take measures aimed at restoring to citizens the ability to find the means of acquitting their rights for themselves.

Because the *Buckhannon* ruling is based on statutory interpretation and is not a constitutional decision, *NCD recommends that the Administration consider and pursue legislation that will modify this decision.* These legislative changes (which should be applicable to all the civil rights statutes providing private rights of action) should provide that where an administrative complaint or court suit identifies practices, procedures, or policies the defendant is moved to change in the context of, during the pendency of, or as a result of the litigation, courts be authorized to award reasonable attorneys' fees according to the same standards that were in effect prior to *Buckhannon*. Naturally, the earlier in the litigation process the reforms are voluntarily implemented by the defendant, the less these fees ordinarily would be, thus creating an incentive for defendants to settle meritorious cases quickly.

No evidence has been adduced of lawsuit abuse by disability civil rights attorneys. Indeed, judging, for example, from empirical research showing that only a small fraction of ADA cases ever result in any relief to the plaintiff, and judging from the widely reported shortages of attorneys to handle such cases, there seems little risk that restoring the pre-*Buckhannon* status quo would have any conceivable adverse effect.

At a time when the DOJ's resources may be focused on compelling issues of national security, enforcement of civil rights laws is likely to become a rearranged priority. Under these circumstances, giving persons with disabilities strengthened means for protecting and enforcing their own rights through the courts, as the law allows them in theory to do, is imperative. Without access to counsel, these established rights will become illusory, except for those few with the wealth or other resources to pay for private counsel or who can obtain the small amount of pro bono legal service that is available.

c. SECTION 1983

Traditionally, Section 1983 (42 USC Sec.1983) has afforded legal recourse to individuals aggrieved by violations of their rights under federal law, including violations by state and local governments and agencies. Americans with disabilities have used Sec.1983 in Medicaid and other settings to protect their rights and to win relief from a variety of unlawful practices.

In 2001, the U.S. District Court for the Eastern District of Michigan ruled in *West Side Mothers v. Haveman*[53] that Sec. 1983 does not permit private lawsuits to enforce the federal Medicaid law against a state. Although two other district courts have rejected the *West Side Mothers* reasoning, the decision, if upheld by the Court of Appeals for the Sixth Circuit, where it is scheduled to be argued in late January 2002, will deny access to the courts to Medicaid recipients or applicants who believe that states have violated the federal statute in their implementation or interpretation of the law.[54] If this occurs, only oversight on the part of the Centers for Medicare and Medicaid Services (CMS), the federal agency with responsibility for the Medicaid program, will hold any realistic hope of redress.

Once again, because *West Side Mothers* is predicated on the interpretation of statutes, means are readily available for curtailing its potentially disastrous effects (should it be affirmed on appeal, or even without waiting for the appellate process to be concluded). In addition to aggressively participating in the appellate process (including at the Supreme Court level, if necessary), the DOJ should develop and submit to Congress on a high priority basis legislation to clarify and reinstate the long-held and broad-based understanding of the settled law that preceded the district court's decision.

d. INTENTIONAL DISCRIMINATION

For the civil rights litigant who can find an attorney and who can avoid dismissal of his or her case under any of the decisions previously discussed, a significant challenge remains. Once

actually in court, this litigant must prove that discrimination has occurred. Yet another 2001 Supreme Court decision, *Alexander v. Sandoval*,[55] may make this materially more difficult to do.[56]

The *Sandoval* case did not deal with a disability rights statute. It concerned Title VI of the Civil Rights Act of 1964, but because of the relationship between Title VI and Section 504 and Title II of the ADA, its logic could have a major impact on the availability of redress under those statutes. In essence, *Sandoval* decreed that Title VI of the Civil Rights Act requires a showing not only that discrimination occurred but also that it was "intentional." Policies, practices, or actions that merely have a "disparate impact" will not therefore ordinarily qualify for coverage.

This matters to litigants with disabilities because Section 504 of the Rehabilitation Act (barring discrimination on the basis of disability by federal agencies and by recipients of federal financial assistance, including state and local government agencies administering federally funded programs) and, to a lesser extent, Title II of the ADA are modeled on Title VI of the Civil Rights Act. Consequently, interpretations of Title VI emanating from the Supreme Court may well be applied to the interpretation and application of these other laws.

Lower court decisions in the aftermath of *Sandoval* are inconclusive, but obviously, if any degree of intentionality must be pleaded and proved, many policies and actions that exclude or restrict the options of people with disabilities, but that do so out of indifference rather than animus, may fall outside the protections of the law. Will it be enough to prove that a defendant knew about the adverse and disparate impact of a particular policy or practice but took no action to remedy it? Will that suffice to demonstrate, if not animus, then at least knowledge amounting to intention? And if a defendant claims that its refusal to take requested action was based on its good faith belief that the accommodation would be an undue burden to it, or on the belief, admittedly mistaken but allegedly sincere, that the person making the request did not meet the legal standard for being a person with a disability, would such defenses serve to overcome the required element of intention?

In the end, who intends to discriminate? Surely very few people do. Most people who discriminate believe they are acting in their best interests, believe they have good reasons for what they do, or believe that unreasonable demands are being made upon them. How is their intention to be assessed?

Many rights currently taken for granted under Section 504 and Title II of the ADA can readily be seen to be vulnerable under an intentional discrimination standard. Application of the *Sandoval* rationale to disability rights cases may, moreover, have consequences far more severe than those attributable to its use with other civil rights constituencies. This is so because, while a defendant may not credibly be able to contend that he or she was unaware of the impact of his or her decisions and actions on minorities or women, the same claim may be all too truthful when impact on people with disabilities is involved. For example, if a government agency is unaware of the existence of assistive technology (AT) that would facilitate "effective communication" with an individual who has a disability, then any degree of intentionality, even of consciousness, may be difficult or impossible to sustain. Once a source of embarrassment, ignorance may become a legal virtue.

NCD recommends that the DOJ and Congress immediately begin efforts to find means for limiting or rolling back the Sandoval *decision, not only as it may relate to individuals with disabilities but also as it bears on the lives and rights of all civil rights constituencies.* At the very least, Title VI and its progeny should be amended to impose a meaningful due diligence requirement on civil rights defendants, so they cannot claim ignorance of disparate impact as a defense to a discrimination charge. If, with due diligence, the discriminatory impact could have been foreseen or remedied, a strong presumption of the requisite intentionality should be deemed as a matter of law to exist.

8. AMICUS CURIAE BRIEFS

As access to Congress becomes more and more the province of powerful lobbyists and special interest groups and elections come to be increasingly dominated by large contributors, the courts have emerged as the only branch of government to which the individual citizen can be assured of meaningful access and a fair hearing. If the courts are to become less accessible to ordinary citizens, including people with disabilities, the role of the Federal Government in defending and defining these rights can only grow greater and more profound.

The U.S. Solicitor General's Office is responsible for representing the United States, as a party or as an amicus (friend of the court), before the Supreme Court. In either role, the Solicitor General's Office plays an important role in setting the legal agenda, in bringing key facts and law before the justices, and in determining the shape and substance of the law in our nation. In the lower courts too, the DOJ plays a similar role, advancing arguments and interpretations and bringing key facts before the courts, particularly the courts of appeal, through its amicus or intervener role, as well as in the guise of a litigant.

In the discharge of these responsibilities in the disability civil rights context, the stakes have now become higher than they have ever been before. NCD has had a number of opportunities to commend and to express its appreciation for the positions taken by the DOJ in key cases over the past few years. Most recently, DOJ's brief in the *Sandusky* case[57] (involving the impact of *Sandoval*) has earned our strong approbation and respect. To be sure, in a few instances the DOJ's position has been adverse to the legal rights of individuals with disabilities,[58] but we have taken note of these, too.

NCD does believe that measures can and should be taken to improve the odds, so to speak, and to ensure that in reaching its determinations of whether and how to intervene, and of what arguments to advance, the DOJ could benefit significantly from systematic and structured input

from the disability community. NCD has endeavored to provide such input whenever possible, but broader input may also be useful.

Therefore, the DOJ should develop procedures for disability community input into amicus briefs filed on behalf of the United States in the Supreme Court on major civil rights cases that the Court has deemed sufficiently significant to review. If these experimental consultative procedures prove useful, they should be extended to the circuit courts of appeals.

When a federal agency undertakes to promulgate regulations interpreting or applying statutes, it ordinarily seeks public comment before finalizing its proposed rules. Indeed, the law requires a public notice and comment process in most such instances. When the Federal Government files an amicus brief with the Supreme Court urging a particular interpretation of the law, it is in effect doing much the same thing. In fact, where it argues for a change in the law or for a reinterpretation of prior decisions, it is doing much more than could ordinarily be accomplished by regulatory action, because for the most part agencies cannot use the regulatory process to change the law. Yet, in the exercise of its amicus jurisdiction, the government is accountable to no one for the interpretation it urges and need never give any reason for choosing to endorse one interpretation of the law over the alternative being pressed before the court.

No one can or should restrict the right of DOJ to develop and advocate the positions it deems best, but in areas where specialized knowledge and unique experience are so critical to the exercise of wisdom, links between the department and affected communities are vital.

DOJ's amicus jurisdiction has contributed to many excellent court decisions in civil rights cases, but it may have helped to bring about some adverse ones as well. Although the DOJ has full legal discretion to endorse any interpretation of the law it chooses and to seek to enter cases as an amicus whenever it deems appropriate (except of course when asked for an opinion by the court, in which case it must respond), the department would frequently benefit from consultation with the disability community. Such consultation could help the department identify which cases

warrant attention through its limited appellate resources, to identify the issues of most concern in the civil rights arena, and to ensure that positions taken in particular cases are consistent with the overall framework of public policy in the area.

In the case of *Chevron v. Echazabal*,[59] the Supreme Curt considered the availability to defendants of the affirmative defense of "dangerousness to oneself" under the employment provisions of the ADA.[60] Specifically, the question posed before the court is whether the ADA allows an employer to refuse to hire an individual with a disability if the job would pose a hazard, not to others, but to the prospective employee's health. DOJ officials, apparently after meeting with disability community representatives and indicating an intention not to, have filed an amicus brief endorsing the defendant's position.[61] In doing this, DOJ endorsed a position NCD believes to be inconsistent with established civil rights case law in the gender area, in which refusal to give pregnant women jobs that are deemed dangerous to their health has been held discriminatory. If DOJ chooses to argue that the gender precedent should not be extended to disability, it should not shrink from telling the affected community, preferably before filing its brief, either why it believes the distinction to be warranted or why it believes the gender decisions to have been incorrectly decided.

A streamlined consultative process, conducted with full appreciation of the time constraints applicable to the judicial process, could help to clarify such issues and could ensure that the views of the disability community are heard by the Solicitor General and other appropriate officials before these officials determine what they want the law of the United States to be. Accordingly, *DOJ, working in collaboration with NCD, should establish a consumer advisory committee or a judicial watch committee, modeled on NCD's Tech Watch Advisory Committee, to identify emerging court cases and legal issues of particular concern to disability civil rights and to advise the attorney general and the solicitor general regarding the exercise of their amicus jurisdiction.*

Our courts properly place great reliance on the recommendations of the nation's chief law enforcement agency regarding how difficult and complex issues of public policy and statutory interpretation should be resolved. Those officials owe it to the nation to ensure that their legal knowledge is adequately supplemented by knowledge of the lives and concerns of Americans with disabilities when they make recommendations and offer analyses that transcend implications for the destinies of these Americans.

The advisory panel we here urge should be composed of lawyers and scholars with disabilities and other disability advocates with extensive experience and knowledge of the issues. It would consult with the department under terms of the strictest confidentiality and, consistent with the provisions of the Federal Advisory Committee Act and other relevant laws, would understand that its recommendations cannot be binding. All that it would ask or seek would be the opportunity to discuss fully with the department the issues involved in key cases before DOJ determines the posture to adopt before our courts.

Chapter 3
Education

America stands at a crossroads in its approach to public education. In December 2001, the No Child Left Behind Act (NCLBA)[62] was adopted by Congress. Representing a revision of the Elementary and Secondary Education Act of 1965 (ESEA), this legislation charts a new course in our nation's educational policy, in the expectations placed on public schools, in the allocation of resources for education, and in the relationship between the Federal Government and the states in the achievement of quality education for all children.

At the same time, we stand poised to address the many issues surrounding reauthorization of the Individuals with Disabilities Education Act (IDEA), which is due for reauthorization in 2002 and hence for review by the current Congress. Many of the basic principles and policies underlying the No Child Left Behind Act are likely to be advocated as guideposts for, and will find their way into, the reauthorized IDEA.

Despite efforts from a number of sources to get specific disability- or IDEA-related provisions into the NCLBA legislation, the key issues and controversies surrounding IDEA have been largely left to the reauthorization debate this year. Provisions on student discipline (calling for the removal from class and the suspension of special education services for special education students who violate rules of behavior) and dealing with funding (calling for the full funding by the Federal Government of the special education program) were contained in both the House and Senate versions of the bill but were omitted from the final NCLBA bill by the conference committee.

Nevertheless, through NCLBA's emphasis on the needs of disadvantaged children, the new law, although more general in its coverage, does apply to students with disabilities in several important ways. As students facing educational disadvantages, children and youth with

1. IMPLEMENTATION OF NO CHILD LEFT BEHIND ACT

If the NCLBA and the forthcoming reauthorized IDEA are to work harmoniously and seamlessly together, the implications of NCLBA for special education and students with disabilities must be thoroughly known and clearly understood. Therefore, as an aid to Congress in its deliberations on IDEA, and as an element of the government's implementation of NCLBA, the Department of Education (ED) should undertake a comprehensive assessment of all the ways in which NCLBA bears on or modifies existing law and regulations concerning students with disabilities, the obligation of states and school districts toward these students, the requirements for state monitoring of special education services and programs, and related issues.

The potential for confusion and inconsistency between the two laws, if this assessment is not made, is amply illustrated by the issues surrounding the applicability of new testing requirements and schoolwide and districtwide accountability standards to students receiving special education services. On August 24, 2000, the ED's Office of Special Education Programs (OSEP) issued a guidance document, *Questions and Answers About Provisions in the Individuals with Disabilities Education Act Amendments of 1997 Related to Students with Disabilities and State and District-wide Assessment.*[63] This document addressed such issues as (a) when does a state (or local education agency) need to conduct an alternate assessment; (b) what an alternate assessment is; and (c) whether individualized education program (IEP) teams may exempt children with disabilities from participating in the statewide or districtwide assessment program.

NCD commended the department in last year's annual report for this response to the previously unanswered questions posed by practitioners, administrators, and policymakers responsible for improving educational outcomes for children and youth with disabilities. Now, even without regard to IDEA, the changes made by NCLBA may well call into question the continuing vitality and relevance of this guidance. Some of the answers and possibilities can be gleaned from a reading of the NCLBA statute and review of its legislative history,[64] but additional answers, not necessarily self-evident from the words of the new law, are required, both to give school

administrators, students, and their families the answers they need now and to assist Congress as it grapples with the complex and daunting issues involved in the reauthorization of IDEA. Although the implementing regulations for NCLBA are unlikely to be completed or adopted prior to Congress's completion of work on the reauthorization of IDEA, the ED should not need to resolve all the details of its implementation strategy in order to be able to specify the impact of the act on IDEA.

The need for this reconciliation is further dramatized by features of the congressional debate over the NCLBA bill itself. In the course of its work on the bill, Congress heard a number of calls to include amendments to toughen the student disciplinary provisions of IDEA. Largely absent from this debate was a baseline recognition of exactly what the discipline provisions in IDEA already were.

2. NCD'S ASSESSMENT STUDY OF IDEA

By way of background to the discussion of IDEA reauthorization, NCD directs congressional and public attention to a document highlighted in our 1999-2000 annual report. In January 2000, as part of its civil rights enforcement series, NCD released a report that focused attention on public concerns about 25 years of monitoring and enforcement of IDEA. Overall, this report, *Back to School on Civil Rights*,[65] found that federal efforts to enforce the law under administrations of both parties have been inconsistent and ineffective. Enforcement is too often the burden of parents, who must invoke formal complaint procedures and request due process hearings to obtain the services and supports to which their children are entitled under the law. In addition, NCD consistently learned that parents of children with disabilities are enthusiastic supporters of the law. They think it's a good law. They also told us there is room for improvement on the law's implementation and enforcement.

One of the things that made *Back to School on Civil Rights* particularly compelling was its inclusion of findings based on the ED's own monitoring reports compiled over the years. These

reports combined to show that 90 percent ($n = 45$) of states were out of compliance with required general supervision requirements designed to ensure that local educational agencies carry out their responsibilities under IDEA. In addition, 88 percent of states had not provided appropriate transition services to help students move from high school to post-school and adult living activities, and 80 percent of states had failed to provide a free appropriate public education (FAPE) to students with disabilities.

Back to School also found that despite long-standing noncompliance with these and other IDEA provisions, the ED had made only limited use of enforcement through its sanction authority. Although the ED had begun to carry out a revised monitoring system (Continuous Monitoring Improvement Process), the department had failed to include clearly elements that addressed public concerns about the lack of consistent criteria for making noncompliance findings and for applying effective enforcement strategies, including triggers for the use of sanctions.

Based on these findings, NCD recommended in last year's report that Congress authorize and fund the DOJ to independently investigate and litigate IDEA cases as well as to administer a federal system for handling pattern and practice complaints filed by individuals.

NCD also recommended that IDEA budget appropriations include a 10 percent set-aside provision for complaint processing, as described in the *Back to School* report. Supported by joint agreements governing audit procedures among the ED, the DOJ, the General Accounting Office (GAO), and the Office of the Inspector General, this approach to complaint resolution would greatly enhance efforts to reduce the disproportionate burden of enforcement parents of children with disabilities have endured in expensive due process hearings and court proceedings over the past 25 years. All these findings have clear and direct implications for IDEA reauthorization, as discussed later in this chapter.

3. THE PRESIDENT'S COMMISSION ON EXCELLENCE IN SPECIAL EDUCATION

On October 2, 2001, President Bush created by Executive Order 13227 the President's Commission on Excellence in Special Education.[66] The commission was scheduled originally to submit its final report by April 30, 2002, but this date has now been extended to July 2002.

Because the findings and recommendations of any such commission necessarily must be informed by philosophical and value-based considerations, having the benefit of the broadest range of experience and opinion is vital for the commission. For the work of the commission to be meaningful, its report needs to reflect outreach to those with this broad range of perspectives. Because the commission convened its first organizational meeting only on January 15, 2002, NCD is concerned whether the commission will be able to hear, digest, and synthesize the necessary range of information and the relevant body of data in time to make a significant contribution to the congressional reauthorization debate. In a similar vein, NCD is concerned that timely IDEA reauthorization efforts across branches of government may be affected by delays in the completion and transmittal of the commission's final report.

As important as values and principles are and ought to be in the deliberations and conclusions of the commission, resolution of many of the most contentious issues surrounding reauthorization depends on a close reading of the factual record. Unfortunately, because different observers can draw sharply divergent conclusions from the same body of data, even a commitment to evidence-based policymaking cannot ensure the development of consensus around recommended reforms. For example, evidence of weak enforcement of the law can be seen as proving that the Federal Government has failed in its IDEA oversight responsibilities. By the same token, such data can be viewed as supporting the contention of IDEA critics that the statute is cumbersome and difficult to enforce. Likewise, evidence regarding the burdens and costs associated with efforts by parents to obtain necessary services for their children can be seen by some as indicating that IDEA has promoted an overly litigious environment, whereas others regard such data as

demonstrating the steep uphill path families still have to climb to obtain the services to which they are entitled by law.

In resolving these and a host of other philosophical and empirical questions, *NCD recommends that Congress and the commission look at the evidence.* For example, in view of the fact that the findings of widespread state noncompliance with monitoring and other responsibilities under the law emanate from the ED's own data, the burden of proof must surely be borne by those who argue that federal oversight has been adequate, let alone excessive. Similarly, for those who contend that the due process provisions of IDEA are excessive or have intimidated school officials or fostered an unduly litigious atmosphere, the relative rarity of successful appeals against local authorities' decisions and the unreimbursed out-of-pocket costs incurred by many parents in pursuing their children's educational needs are facts that cannot be ignored.

Accordingly, *NCD recommends that the National Commission and Congress give these and other findings a full airing, confident as we are that if all evidence and points of view are fully incorporated into their deliberations, the best possible results will be obtained.* In this connection, the commission's charter gives grounds for concern. Taking as its point of departure the virtually indisputable premise that special education is not working well, or not working as well as it should, and embracing the search for research and ideas to make the system better, the commission's charter contains no instruction to investigate the possible role of long-term noncompliance, lack of enforcement, and minimal monitoring and oversight as explanatory factors in the deficiencies of the current system. In light of *Back to School on Civil Rights,* this omission seems particularly unfortunate, because without attention to oversight and enforcement, new approaches are very likely to fall short of fulfilling their potential and goal, just as the old approaches have done.

4. IDEA REAUTHORIZATION RECOMMENDATIONS

As part of its contribution to the unfolding debate, NCD wishes to address a number of specific matters that are likely to be controversial in the reauthorization discussion.

a. ENFORCEMENT

As mentioned previously, NCD findings from *Back to School* indicate that for more than 25 years and through several administrations, federal IDEA enforcement efforts have consistently lacked "teeth." When a state is found out of compliance with IDEA, the Office of Special Education Programs works with the state on the development of a compliance plan and provides technical assistance on the implementation of that plan. This strategy has not solved the problems, especially when no clear, objective criteria for additional enforcement options exist. Currently, no clear and effective (positive or negative) standards and strategies exist for a state that continues substantial and persistent noncompliance. The result has been devastating for the students with disabilities and their families who are denied the protections of the law. Without standards that define the limits and provide appropriate sanctions, the incentives for corrections have not been compelling enough to stop the cycle of noncompliance. *NCD believes that this issue has reached a crisis point and recommends bold steps to correct it:*

1. The Department of Education should not be the sole enforcement agency. The ED has long-standing and collaborative relationships with state education administrators. These important relationships are jeopardized when the ED threatens sanctions. Partial solutions were included in the last reauthorization when enforcement authority was also given to the DOJ, but only following referral of cases from the ED. This has not worked; there have been no referrals to the DOJ since that authority was added to IDEA. To address noncompliance problems, *NCD recommends an expansive role for the DOJ. Congress should authorize and fund the DOJ to independently investigate and litigate IDEA cases, as well as administer a federal system for handling pattern and practice complaints filed by individuals.*

2. The lack of national standards is at the root of the enforcement problems. *NCD recommends that the Departments of Education and Justice be directed to develop national compliance standards, improvement measures, and enforcement sanctions that will be triggered by specific indicators and measures indicating a state's failure to ensure*. Stakeholders, including students with disabilities and parents, should be consulted by the departments for consistency and clarity as they develop and implement a range of enforcement requirements.

3. Families members and students are very strong stakeholders in the enforcement of IDEA. In fact, as pointed out earlier, they have been the true enforcers of the law. Critical to their effectiveness, however, is the availability of free and low-cost legal advocacy through public and private legal service providers. Equally important are training and technical assistance programs for students to expand their self-advocacy skills. Finally, there are other important partners in this process; collaborative participation should be encouraged by special and regular education teachers and agents of relevant systems, such as INS, child welfare, and juvenile justice systems. *NCD recommends that Congress authorize more funding for Department of Education-sponsored technical assistance programs to support the development of state-level technical assistance networks; self-advocacy and monitoring training for students, parents, and other partners; and free and low-cost legal services for families. NCD recommends that IDEA include a formula that triggers the funding of these activities at an amount equal to 10 percent of the total increase in Part B funding.*

b. DISCIPLINE

Because of a few widely publicized cases, many people appear to believe that IDEA bars schools from taking disciplinary action, including removal from the classroom of dangerous or disruptive students, with students who are receiving special education services. That is not the case, but the existence and frequent public repetition of this erroneous belief complicates and adds emotion to the discussion of how the uniformly shared goals of classroom discipline and order can be

squared with the provision of appropriate special education and related services to all students, including students with behavioral problems arising from unaddressed physical, emotional, or cognitive causes.

As noted, discipline amendments to IDEA were proposed but ultimately rejected in NCLBA. As these issues prepare to surface again in the IDEA reauthorization debate, NCD points out that if no child is to be left behind, that commitment applies to students with disabilities as well. No child should be denied needed educational services. Rather, the services must be designed and delivered in an environment and a manner that are appropriate to each child's needs. We would not allow a parent to keep a child out of school on the basis of that parent's belief that the child was uneducable, incorrigible, or dangerous. Were we to allow education officials to deny services to children who need them, and in the end to deny all education to such children, the practical results would be essentially the same. Accordingly, children should never be considered to have forfeited their right to services, because education, including special education services, is not something to which a child must earn entitlement or which a child, any more than a parent, can waive.

As a further backdrop to the discussion of student discipline, NCD also notes, as we have previously done, that student behavioral problems cannot be understood or addressed in a vacuum. By recognizing that the school environment, the level and quality of services, and other elements of the school setting significantly influence student behavior, we do not condone or rationalize bad behavior. By acknowledging that behavioral problems are frequently not volitional, we do not obscure the distinctions between right and wrong. Accountability must apply to student behavior, but, as discussed below, accountability must apply no less to states and school districts. If students are "warehoused," if they are denied the technology and services necessary for meaningful participation, or if they are not challenged to achieve their maximum potential with appropriate positive behavioral supports, the occurrence of some behavior problems can come as no surprise. And if appropriate diagnostic and assessment services, as well as needed remediation, are not available, the links between behavior and underlying emotional conditions, though often obvious, may never be elucidated or addressed. Notwithstanding the

perceived need to streamline a deliberately complex process, *NCD recommends that the current protections on the discipline of students eligible for Part B IDEA remain unchanged.*

c. OVERREPRESENTATION FROM DIVERSE BACKGROUNDS

One of the great concerns of many observers of IDEA is the statistical overrepresentation of children from African American and other diverse backgrounds among children and youth deemed eligible for special education services and designated as students with disabilities for purposes of IDEA.[67] To some degree, this overrepresentation may reflect the interaction of disability with economic, social, or other forms of disadvantage, ranging from heightened exposure to lead toxicity in many inner-city areas to poor nutrition or the destabilizing effects of violence in all too many neighborhoods. At the same time, the suspicion is widespread that this overrepresentation of diverse students in the special education population is the result of "dumping" these students out of the academic mainstream by school systems that are for any of a number of reasons unable to achieve educational success with them.

The Bush Administration has demonstrated concern over this pattern of overrepresentation, particularly as it manifests itself in disproportionate numbers of diverse students being diagnosed with emotional disabilities or with developmental disabilities. As Secretary of Education Roderick Paige stated at an October 2001 hearing: "African-American students are labeled as mentally retarded and emotionally disturbed far out of proportion to their share of the student population. Department of Education national data show that 2.2 percent of all black students, but only 0.8 percent of all white students, are identified as mentally retarded. Similarly, 1.3 percent of all black students, and only 0.7 percent of all whites are identified as emotionally disturbed.... For minority students, misclassification or inappropriate placement in special education programs can have significant adverse consequences, particularly when these students are being removed from regular education settings and denied access to the core curriculum. Of particular concern is that, often, the more separate a program is from the general education setting, the more limited the curriculum and the greater the consequences to the student,

particularly in terms of access to postsecondary education and employment opportunities. The stigma of being misclassified as mentally retarded or seriously emotionally disturbed, or as having a behavioral disorder, may also have serious consequences in terms of the student's self-perception and the perception of others, including family, peers, teachers, and future employers."[68]

Thus, as all agree, a response to the problem of overrepresentation is urgently needed, but that response must be appropriate and effective. Some will argue that eligibility for special education services, particularly in the area of learning disabilities and attention deficit and hyperactivity disorder (ADHD), represents the best solution to the problem. If special education amounted in practice to nothing but warehousing, or if evidence showed that students were classified as special education students only so that school districts could receive per capita federal funds while providing little or no service, then indeed many students might be better off without it. But if special education services are responsive to the learning issues faced by many students, and if the program is monitored to ensure that "least restrictive environment" (LRE) requirements aimed at keeping students with disabilities in the appropriate placements are enforced, then restriction of eligibility for services constitutes the proverbial throwing out of the baby with the bathwater.

The diagnosis and remediation of ADHD and related conditions is fraught with methodological issues and is often more subjective than it should be. Too often, the suspicion seems warranted that ADHD is a diagnosis made for the administrative convenience of the school or even for the financial gain of pharmaceutical companies. But the solution is to marshal the resources of science to develop objective diagnostic tools and to test and validate intervention strategies, going beyond amphetamine-type or other drugs, that have shown promise and demonstrated effectiveness in these settings.

Prior to taking any action to restrict eligibility for special education services, especially by limiting the diagnoses that qualify for the program, Congress should commission an exhaustive

study of the issue by leading medical, educational, behavioral, and other scientific and legal experts. Such a study does not appear to be within the charge of the President's Commission and probably could not be completed in time to illuminate this year's reauthorization debate.

d. DUE PROCESS

Various critics of IDEA believe that the due process and appeal rights it affords parents constitute an invitation to excessive litigation, unduly enrich lawyers, and interfere with the ability of educators to implement appropriate plans and decisions for students with disabilities. Regardless of the cogency of these views, they reflect a radical shift in philosophy regarding the proper role of parents in the educational process.

During the quarter century since its enactment as the Education for All Handicapped Children Act of 1975 (P.L. 94-142), IDEA has embodied a commitment to parental participation in the formulation of educational interventions for their children. Under current law, parents have the right to participate in and to agree to the provisions of their child's individualized education program (IEP). The right to appeal when they are excluded from this decisionmaking process or when the results of the IEP process do not conform to their sense, borne of the most intimate familiarity, of their children's needs is surely a central feature of the overall statutory commitment to family involvement in the education of children.

In many other ways, IDEA favors measures to encourage and promote parental participation in the education of their children. To the degree that parental involvement is deemed to include some measure of consent to the measures adopted for their children, and to the degree that the IEP remains an individualized plan that must be tailored to the needs of each student, asking the proponents of due process curtailment how they would protect the parental rights that the law now enshrines is fair. Litigation is not the preferred strategy for enforcing parental rights. Out of just such an agreement, the IDEA Amendments of 1997 included a number of provisions designed to reduce the instances in which litigation would be necessary, including provisions for

a negotiating process before any due process appeal proceedings could be instituted. At the very least, before agreeing to any further curtailment of family rights under IDEA, Congress should examine the impact of these recent amendments, especially as they relate to the availability of attorneys' fees under the law.

In this connection, Congress is likely to face calls for further narrowing or even for elimination of the entitlement to attorneys' fees for "prevailing parties" in IDEA appeals. Before yielding to such calls, and before imposing any other procedural limitations on the ability of parents to assert and defend their children's rights and needs, Congress should consider what avenues would be available to parents of moderate or limited means for pursuing in good faith their children's IDEA rights if legal recourse were further foreclosed to them. One result of further curtailment of attorneys' fees would surely be that only wealthy parents would be in a position to enforce their children's educational rights when school systems failed to do so.

Indeed, Congress should do more than simply avoid adding further constrictions in this area. Because the *Buckhannon* redefinition of "prevailing party" may be applied to IDEA by the courts, thus resulting in attorneys' fees rarely if ever being awardable under the statute and in due process appeals becoming largely unavailable to those without the financial means to hire counsel or the bureaucratic skills to advocate on terms of equality with the lawyers and educators representing the school system, Congress should make clear in the reauthorized language that for purposes of IDEA, the definition of "prevailing party" remains as it has been.

If Congress remains concerned that either attorney fee availability or parental involvement or other family due process rights are interfering with the educational process, it should commission a study, employing empirical and evidence-based tests and data-gathering instruments, to determine the real impact of due process provisions on the prevalence and outcomes of IEP litigation and, indeed, on the impact of parental involvement and due process rights on the quality of special education and on the character of all education throughout this country. If Congress does this, it is likely to reach one of two conclusions. Either it will find that successful

appeals from IEP decisions are numerous (in which case the school systems in question have arguably failed to properly interpret or apply the law) or that successful appeals are scarce (in which case, because no legal fees are available for nonprevailing parties, the availability of legal fees from "deep-pockets" school districts could hardly explain the filing of the majority of cases).

For all of these reasons, Congress should resist any attempts to diminish parental participation/consent, appeal rights, or attorneys' fees and other due process rights in the reauthorization of IDEA.

e. ASSISTIVE TECHNOLOGY

In 1997, Congress strengthened the requirements of IDEA pertaining to assistive technology (AT) by requiring that the need for technology be considered as an element of the IEP assessment process. But in practice, all this means is that a box on a form needs to be checked. In fact, while some states include this item on mandatory or advisory IEP documentation or checklists used by school districts, other states do not, meaning that in some places there may not even be a box to check.

Given the growing importance of technology in the educational process and the rapidly expanding capability of AT to mitigate a range of functional limitations, checking a box is no longer enough. NCD believes that when a school district denies AT, information should be provided regarding what was tried and rejected, including a clear rationale.

Inclusion of such a provision should not place administrative burdens on school districts, because if AT has in fact been considered, as the law already requires it to be, then the personnel who designed and approved the IEP will surely know what technology they considered and why it was accepted or rejected. Nor need this new provision be the source of additional disputes between parents and school districts. To ensure that it will not be, *NCD recommends that the*

data explaining AT decisions be collected solely for monitoring and oversight purposes and that it be used by states and by the ED only in its aggregate, nonindividually identifiable form to evaluate overall trends in assessment and service delivery, as well as for anticipating personnel preparation and specialization needs.

f. ACCESS TO SCHOOL TECHNOLOGY, INSTRUCTIONAL MATERIALS, AND MEDIA

Today, current laws require that newly constructed schools need to be physically accessible to students, staff, and parents with mobility disabilities. Yet, the closely related premise that school computers, textbooks, and other instructional materials and media must be accessible to all students remains far from self-evident in the minds of many policymakers and educational practitioners. One cause for this delayed recognition may be the belief on the part of some that accessibility of the school information infrastructure and of the curriculum is a responsibility that must be met out of special education funds. We would not accept this view with regard to ramps and other architectural features. How can such a view be sustained with regard to the ramps to the information superhighway provided in and by schools?

The notion that accessibility is a special education function appears to derive from the mistaken belief that accessibility is implemented on behalf of individual students. But if one waits for an individual student to request such access, it will almost certainly be too late. In reality, if one builds the infrastructure without reference to accessibility, retrofitting to accommodate the needs of an individual student is more difficult and costly than otherwise need be the case. Only if the law makes clear that information and curriculum access is no different than physical access—to the parking lot or the bathrooms or the classroom itself—can the necessary planning and funding be brought into play. Accordingly, consistent with existing legal requirements under Section 504 of the Rehabilitation Act (and possibly, depending on the outcome of the ED deliberations on the point, under Section 508), IDEA reauthorization should make clear that accessibility of information technology and curricular materials is a responsibility of school systems, irrespective

of the needs assessment of any particular child with visual, hearing, or other communication disabilities.

In this connection, NCD commends the National Institute on Disability and Rehabilitation Research (NIDRR) for its funding of the ADA Disability and Business Technical Assistance Centers (DBTACs) to provide technical assistance to the nation's schools in the achievement of access to education and information technology. NCD particularly recognizes the creation of the National Center for Accessible Education-based Information Technology, which has been funded to provide technical assistance to the ten regional DBTACs in carrying out their important new responsibilities in the educational technology sector.

Congress should ensure in the IDEA reauthorization that adequate authority and resources are made available for the provision of technical assistance to state education departments and local educational agencies (LEAs) throughout the country regarding the legal requirements of the law concerning accessible school computers, audio-visual materials, and textbooks. Such technical assistance, along with the statute itself, should make unmistakably clear that information and technology accessibility are not special education concerns, because they are responsibilities that are not triggered by the needs of any particular student. And most important, such technical assistance should include substantial guidance on what information accessibility means and on the techniques, technologies, and design strategies that will help bring it about.

g. DISABILITY HARASSMENT

As noted with approval in NCD's 1999-2000 annual report, on July 25, 2000, the ED's Office of Civil Rights (OCR) and its Office of Special Education and Rehabilitative Services (OSERS) jointly issued a document pertaining to disability harassment.[69] The document addressed (1) why disability harassment is such an important issue; (2) what laws apply; (3) how to prevent occurrences and how to respond; and (4) where technical assistance is available to the public.

The document provided examples of harassment that could cause a hostile environment, resulting in adverse effects on a student's ability to participate in and benefit from the educational program. In addition, the document contained examples of harassment prevention and elimination measures that may be effective.

In recent years, our nation has made substantial progress in addressing sexual harassment in schools, and indeed in responding to all forms of bullying and intimidation. Disability harassment must be addressed with the same vigor and purpose. Consequently, *NCD recommends that Congress in the IDEA reauthorization should adhere to the principles and to the important statement of the law as set forth in the ED document by including strong anti-harassment measures in the law.*

Technical assistance in preventing, identifying, and halting disability-based harassment should be the primary tool of federal involvement, but consistent with the themes of accountability that are likely to be prominent in the law, schools should not be allowed to escape responsibility if their efforts fall short of reasonable expectations or if they fail to implement measures to protect victims and to control offenders. If student discipline is to be an issue in the reauthorization, then student victimization cannot be omitted from the equation either.

h. FULL FUNDING

Several components of IDEA, including Parts C and D dealing with special education and related or supplementary services and dealing with early intervention services, are mandated and must be reauthorized. But within the framework of this mandatory status, considerable room of course exists for the modification of specific Part B provisions. Discipline, as discussed earlier, is an example. Another example, and a long-standing concern among special education advocates, is what is known as "full funding" of IDEA.

Full funding here does not mean that federal funds should defray all the costs incurred by states and local school districts in providing special education services. Rather, the term refers to the fulfillment of the historic commitment, going back to the creation of the special education program 25 years ago, that Congress would appropriate funds to meet 40 percent of program costs. Estimates are that today federal funds meet between 10 and 15 percent of the costs of special education.

At a time when state and local governments find themselves facing acute financial pressures, and when, moreover, they are likely to incur increased expenses in the implementation of NCLBA, the argument for full funding takes on a practicality and an urgency that it may not have had in recent years of surpluses and economic growth. The arguments for full funding go well beyond the strictly economic, however. At times of economic stress, worthy programs and purposes are inevitably thrown into competition as painful choices are made over the allocation of scarce resources. Special education, even in periods of relative fiscal well-being, is all too easily scapegoated in ways that run the risk of pitting students with disabilities against their nondisabled peers in the competition for attention and resources. What is easier for a beleaguered school official who fears to ask the taxpayers for more funds than to say, perhaps even to believe, that without federally imposed special education costs, cuts in popular program areas could be reduced or avoided?

If schools are to face cutbacks because of local funding shortages, the dangers of such scapegoating and of the development of destructive and hostile public and community attitudes toward special education poses a serious risk to the viability and the integrity of the entire effort. NCD recognizes that the Federal Government faces its own fiscal constraints, but there may be few cases in which the investment of additional funds has as much leverage value or an increased federal commitment can do as much to protect and preserve public support for a program that has been and remains a centerpiece of national education policy over the course of nearly a generation.

Congress should take IDEA reauthorization as the occasion for implementing full funding, perhaps over a period of several years, but with proportionally increasing expenditures over each year until the target 40 percent level is reached. To fail to act would be among the most penny-wise and pound-foolish decisions our nation could make.

i. ACCOUNTABILITY

As reflected in the NCLBA, we have entered a new era of federal-state cooperation in the universally shared goal of preparing America's children for the 21st century. Special education must be prepared to change as general education has and will continue to do. The watchwords of the new educational era are "flexibility, accountability, and choice." By applying these watchwords no less to the ways schools provide special education than to the ways they provide general education, we can assure equality of opportunity, which is the goal of all.

Among disability statistics, perhaps the most shocking is that diploma graduation rates for students receiving special education and related IDEA services hover at around 27 percent.[70] Contrast this with an estimated 75 percent for students without disabilities. While room exists for disagreement (and certainly for further research) into the causes of this shocking disparity, no room or time exists for allowing schools to avoid accountability for these results. Particularly now, when NCLBA has made accountability a focal point of national educational policy, we must expect and can tolerate no less for students with disabilities than we have for students without disabilities.

Congress should incorporate clear, meaningful, and enforceable accountability provisions in the IDEA reauthorization, making states and local school districts responsible for the outcomes achieved by all their students and providing technical assistance for those that fall short, as well as rewards and penalties as appropriate. At a minimum, Congress should require that where state graduation rates for students receiving special education services fall significantly below those rates for all students, mandatory and comprehensive technical assistance be required. And where

improvement and movement toward parity are not forthcoming after two years, students with disabilities should be assisted to pursue other educational options, just as students without disabilities in underperforming schools and school districts will now be permitted to do under NCLBA.

Chapter 4
Health Care

As Congress continues to grapple with a number of interrelated issues concerning the costs and availability of health insurance and health care, remembering that Americans with disabilities face a number of distinct barriers in obtaining, maintaining, and using health insurance and in accessing and using health care services is important. At the same time, Americans with disabilities also confront the barriers, problems, and frustrations with which most Americans routinely struggle in the insurance and health care systems.

In a series of reports going back to 1993,[71] culminating most recently in our March 2001 paper on proposed patients' bill of rights legislation,[72] NCD described and tracked both kinds of barriers and made carefully thought-out, balanced recommendations for reform. Against this backdrop of experience and interest, we first address the issues raised by the ongoing debate over a national patients' bill of rights.

1. PATIENTS' BILL OF RIGHTS

The intense interest with which many in the disability community have followed the progress of patients' rights legislation is not difficult to understand. Despite the difficulties they face in obtaining and fully benefiting from health insurance, the majority of Americans with disabilities who are insured receive their coverage through private sector sources. As early as 1993, NCD'S report *Perspectives on Access to Health Insurance and Health-related Services* found that private health insurance, from ERISA-regulated self-insured employer plans and from state-regulated individual and group plans, is the major source of coverage for people with disabilities, whether as primary insureds or as covered spouses and dependents.[73] As our nation grapples with health insurance reform on the federal and state levels, remembering that the decisions we make will affect everyone, including children and adults with disabilities who are among the most vulnerable members of the health insurance population, is critical.

Owing to disagreements on several controversial issues, most notably but not exclusively the issue of health plan liability (the patient's right to sue), Congress adjourned in December 2001 without passing patients' bill of rights legislation. This issue is anticipated to be a continuing focus of reform efforts in the second session of the 107th Congress, and it does not seem unreasonable to expect that compromise legislation will be adopted during 2002.

NCD believes the following key issues must be addressed in this important legislation:

a. COVERAGE

Precisely because so many Americans with disabilities rely on private insurance for their health coverage, applying the legislation to all privately insured persons and to all health care plans is vital. Refusal of coverage to otherwise eligible persons on the basis of disability should be impermissible.

We do not suggest that federal law can or should control the kinds of coverage or types of plans that insurers offer or that insurance purchasers choose to buy. Elimination of exclusionary practices based on disability would not interfere with the ability of insurers to compete on price or benefits and would not prevent employers from offering more or less comprehensive coverage as they see fit.

Some would argue that universal coverage in the sense here contemplated would drive up costs, thereby adversely influencing both the content and the availability of coverage for all. This issue is far more complex than it may appear at first glance. Many factors, including the size and composition of coverage or purchaser groups, the use of annual or lifetime expenditure caps to limit plan exposure on behalf of high-cost users, the availability of preventive and health promotion services, competitive pressures in the insurance marketplace, and many other considerations go into this determination. Moreover, we must remember that in the end somebody pays.

Much of the debate over health insurance coverage is less about who or what should be covered than about cost-shifting. If people with disabilities are denied insurance coverage for which they would otherwise be eligible, then the costs of their disability-related and non-ability-related care alike all too often fall on the public sector. In the absence of any evidence that disability and high use are synonymous, and in the absence of any actuarial data showing that cost differences among large-group plans can be attributed to the numbers of people with disabilities covered by those plans, the denial of coverage on the basis of disability cannot be justified or allowed.

b. ACCESS TO SPECIALTY CARE

For many people with disabilities who are covered by health insurance, a major barrier to adequate care is the inability to obtain specialized kinds of medical treatment and related health care services to improve or to maintain their level of functioning. The issues for this population typically relate not to acute care, nor to post-episodic rehabilitation, but to ongoing services (e.g., seating and positioning for wheelchair users) that prevent the occurrence of functional problems (such as pressure sores) that can in turn lead to medical problems. Physicians and other practitioners and institutions capable of providing the range of necessary specialized services are typically fewer in number than those capable of more routine kinds of general care. For that and other reasons, the fact that many health care plans do not include the needed sources or service categories within their provider networks is not surprising.

In such cases, health plans should be expected to make provision for out-of-network or out-of-panel referrals, and these should be available at the same cost to consumers as in-network services are. Health plans always have the option of including specialized practitioners in their networks and specialized services among the interventions and modalities they cover, but they should not be permitted to effectively deny needed services to beneficiaries with disabilities by limiting care options to only routine services and generalist practitioners.

c. POINT-OF-SERVICE OPTION

Among the general public, point-of-service (POS) options, particularly the right to consult a specialist of one's own choosing, is surely one of the chief concerns that people express with all forms of managed care. For many people with disabilities, this is a pressing issue, in some cases an issue of life and death. If an individual has identified or long been under the care of a practitioner who is uniquely skilled and who is familiar with her particular condition and history, the potential for finding a suitable replacement may be very small, and this is even more likely to be the case in rural or inner-city areas, where medical resources of all types may be thinly spread.

POS options need not be unlimited either as to the range or number of practitioners allowed. Managed care plans have already developed a number of POS options, and it should not be difficult to adapt these to the needs of insured persons with disabilities. Nor need health plans face excessive costs, because they can require POS providers to accept the same reimbursement available to in-network providers and to abide by all other terms of plan participation.

d. CONTINUITY OF CARE

When a practitioner or facility leaves a provider network, or when an employer changes provider networks, major care disruptions can occur. For people with disabilities, who may have complex and specialized care needs and who may have difficulty locating alternative providers, this situation can present pressing problems and real dangers.

As a general matter, network-based health insurers should be required to provide a transition period of at least 90 days, during which members' established providers will be treated as de facto members of the new network. For persons with chronic health conditions or specialized care needs who despite their and the plan's best efforts cannot find a suitable replacement, the law should include provision for extending the transitional period or even, where no willing and available provider exists, for indefinite extension of this option.

Who is an acceptable substitute is a question of fact, but one as to which the judgment of the patient and patient's family should be accorded considerable deference. Because the health plan is not purporting to deny the service and is not paying more than it would have paid to a practitioner of its choosing, this should not have material cost implications for insurers.

e. STANDING REFERRALS

Owing to the gatekeeper principle under which many managed care plans operate, referrals to specialists are often issued on a one-time or otherwise limited basis, with further referrals requiring an additional, reviewable authorization by the individual's primary care physician. Vexing as this process is to many, it is again often a particular problem for people with disabilities, for many of whom their real primary care physician may be a specialist. Because the plan may allow referrals or certain service requests to be made only by designated gatekeepers (primary care physicians/general practitioners), this may mean frequent visits to a physician who has no role in the care of and little ongoing relationship with the patient.

Even if this is not the case, for the individual with a disability who needs regular, ongoing care, the system may necessitate innumerable re-referrals or prior authorizations, with the attendant delays, paper shuffling, and uncertainties associated with such procedures. The law should provide for plans to make open referrals for the regular and predictable specialty care that individuals with disabilities may need. With the duration, number of visits, types of services covered, and other relevant variables tailored to the individual case, these flexible referral practices may actually yield administrative cost savings to insurers and emotional cost savings to insured persons in many cases.

f. TIMELY AND ACCURATE INFORMATION

Given the numerous documents, the complex provisions, and the unfamiliar technical language involved in the administration of health plans, few people are likely to fully understand their

coverage. For this reason, a number of state and federal laws impose disclosure and notice requirements on insurers. Whatever the efficacy of these requirements for the general public, they are of little value for many people with disabilities, such as people who cannot read print evidence-of-coverage booklets or explanation-of-benefits statements because of visual disabilities or people who cannot participate in informational briefings or readily consult with time-pressed practitioners because of hearing disabilities.

Patients' bill of rights legislation should contain requirements for effective communication with purchasers, beneficiaries, and practitioners, including on-request provision of written materials in accessible formats and provision of sign language interpreters and assistive listening technology. In urgent situations where prior authorization for services is required or time limits apply to filing a form, these accommodations can literally make the difference between the availability and unavailability of needed treatment and, perhaps in some instances, between life and death.

The measures suggested here are identical to those required under Title III of the ADA's auxiliary aids and services and effective communications provisions. Whereas most people believe that insurers meet the definition of public accommodations for purposes of coverage under the ADA, replicating these provisions in the patients' bill of rights would nevertheless be useful. That way, any concern insurers may feel regarding their underwriting and other business practices being subjected to ADA scrutiny could be allayed. The insurance industry and Congress should likewise understand that if the information-accessibility provisions here proposed are not included in the patients' bill of rights, efforts by people with disabilities to achieve this access through the ADA or other civil rights laws are certain to intensify.

Other kinds of information are also vital in this connection. Expecting health plans to make informed consent forms, package inserts, usage instructions for drugs included in their formularies, or other similar materials accessible is not unreasonable. Health plans and their subscribers should be accorded flexibility in how this is done, subject to the requirement that effective communication be achieved.

g. ACCESS TO CLINICAL TRIALS

Access through insurance to clinical trials has some intriguing implications for people with disabilities, which may be distinct from its implications for the population as a whole. If the patients' bill of rights includes any provisions regarding such access, these implications should not be overlooked.

When we think of clinical trials, we normally think of controlled experiments designed to evaluate the safety and efficacy of new drugs. But in principle, although surgery and other medical procedures are not subject and often not amenable to evaluation in this way, no inherent reason exists why the research model that underlies the use of clinical trials needs be limited to the testing of pharmaceuticals. Are clinical trials limited only to drugs, or is this methodology available for testing other interventions as well? Put another way, if insurers are being asked to underwrite some of the costs of drug development by paying for patients' participation in clinical trials, would it be unreasonable or infeasible to likewise ask that this resource be available to test the efficacy of assistive devices, community interventions, or services and interventions that, if found beneficial and cost-effective, might well qualify for coverage under health insurance?

Accordingly, if access to clinical trials is included in a patients' bill of rights, Congress should make clear that their use is not limited to pharmaceuticals. The FDA, NIH, or NIDRR should be instructed to develop procedures for registering nonpharmaceutical trials and for ensuring the same quality control that is required in the medication arena.

h. MEDICAL NECESSITY

More than any other criterion for giving or withholding services, the concept of medical necessity lies at the heart of the health insurance system. Advocates of health care reform have sometimes suspected that insurers who use lack of medical necessity to rationalize denials of service have other motives. But even if that is true, the complexity of the assessment, coupled

with the broad discretion traditionally granted to insurers in applying the medical necessity concept, has resisted the articulation of any objective standard that could be consistently or convincingly used to review these decisions.

These characteristics make the medical necessity determination problematic for many people, but for people with disabilities, the medical necessity question has several added dimensions. First, as health plans seek to control costs, definitions of covered services and of what is deemed medically necessary are tending to narrow. Allied health care providers, ranging from speech-language pathologists to occupational therapists and psychotherapists to rehabilitation engineers, report sharp declines in the willingness of health plans to use their services. Yet, services such as these are often the very ones that people with disabilities most need.

Second, insurance decisionmakers, including reviewing physicians in many instances, are unfamiliar with AT, rehabilitation engineering, orthotics, speech-language services, vision and hearing services, or other modalities and inputs that people with disabilities may need. Related to this, many AT devices do not come from traditional or recognized medical sources and thus have a heavy burden of skepticism to overcome.

Finally, many AT devices, personal assistant services, and other interventions that people with disabilities need may improve function or quality of life, but because they do so without resulting in medical improvement as that concept is conventionally measured, they are regarded as functional, rehabilitative, quality-of-life, social, or otherwise nonmedical in nature. For a person with carpal tunnel syndrome, a voice-activated computer input system may make an enormous difference. It may represent the difference between being able and unable to work. It may immensely enhance the quality of life in a variety of other ways. By minimizing stress on the affected wrists, it may in the long run prevent further damage, but because the joint is not necessarily less inflamed or more mobile, the voice-activated system is not considered medical or medically necessary, no matter the good it does.

We live at a time when technology and medicine are converging and when that combination is capable of bringing benefits and achieving results that were unthinkable only a few short years ago. Yet, we also live at a time when the health care system finds itself under increasing economic pressure and when short-term cost competition often assumes transcendent importance in the establishment of coverage policy and in the making of individual case services decisions. In this collision of opposing trends, people with severe disabilities may ironically face yet a further problem. It may be blithely assumed by some that government will provide the technology or other "nonmedical" services and supports they need. As most people with disabilities know, this is anything but routinely the case.

Any definition of medical necessity that is suitable for our day must include a recognition that maintenance and improvement of function is often as or even more important than isolated parameters of medical improvement that may have little to do with quality of life. Our health care system justly prides itself on the increases in life expectancy that have been brought about in large part through its collective efforts. Having extended life, the health care system surely bears some obligation to acknowledge some responsibility for the quality of life. Only by incorporating a more pragmatic, functional standard of improvement or benefit into the equation can the concept of medical necessity be expanded to take fuller account of the needs and opportunities facing Americans with disabilities, and all Americans as our society ages, today.

As it relates to the proposed patients' bill of rights, the key question is whether this pragmatic standard can be incorporated into the definition of medical necessity without undermining the traditional and necessary discretion of health insurers to make these determinations on a case-by-case basis. Put another way, how can insurers be helped and encouraged to use a broader standard of medical necessity without risking loss of discretion or potentially large increases in costs?

NCD believes that two approaches commend themselves for consideration as a way forward from this dilemma. First, because insurer fears over costs will prevent the broadening of the

definition of medical necessity to include AT, *NCD recommends that as part of the patients' bill of rights, Congress should appropriate an amount of seed money, to be administered by NIDRR, for the conduct of a five-year demonstration project aimed at assessing the costs and benefits associated with the judicious provision of AT devices and services within the framework of a major, national health insurance plan.* The program would be carried out by an entity selected by NIDRR for its knowledge and experience in AT and would recruit a major insurer or self-insured plan to participate on terms that limited the participating insurer's financial risk and gave it the freedom to discontinue the project at any time if it deemed it inappropriate or unwise to continue.

Under the demonstration project, skilled AT evaluators and service providers would review all cases, subject to patient confidentiality and informed consent, to determine the appropriateness of AT inputs for the function, independence, and overall capabilities of the individual. On a determination that AT is appropriate, and on joint selection of the technology to be used by the evaluator and prospective user, the necessary devices and services would be provided and their impact on function, future health care costs, and future health status would be carefully tracked. At the end of the study period, a broad range of outcome and other data accrued by project participants would be compared with expected outcomes and costs. NCD believes that the add-on costs would be far less than many fear and that the benefits, in terms of other cost savings to insurers, including to disability insurers and public sector income replacement insurance programs such as Social Security Disability Insurance (SSDI), would substantially offset such additional costs as are accrued.

In the meantime, while this prospective research is being conducted, a parallel research effort designed to gather new insight into how medical necessity decisions are actually made should simultaneously go forward. Functional considerations may in fact play a decisive role in medical necessity determinations far more often than many would suspect. For example, if surgery is available to restore the ability of an individual to walk, it is the ability to walk and the capacity for independent movement, not an increased range of motion of the legs, that is the real

justification for the surgery. Similarly, if a pharmaceutical therapy can restore hearing or vision to a given degree, it is not for the sake of performance on hearing or vision tests, but because of the increased function the treatment affords, that we provide it.

If properly designed research into the motives and reasoning of medical necessity decisionmakers reveals these conclusions to be warranted, then the entire frame of reference for the discussion of medical necessity shifts. In relation to AT, for instance, the issue then becomes not whether the insurance system does or should disregard function, but rather why or whether that system prefers one means for improving function over others that may be equally effective, potentially even at lesser cost. If AT or other nontraditional inputs provide a level of function that is comparable to what an insurer would pay if that level could be attained by established surgical or pharmacological means, what is the rationale for the distinctions that are made between modalities that yield comparable results, paying for some and rejecting others? What is the principled difference between a drug that allows a person to hear well enough to go out to the theater or restaurants again, on the one hand, and sophisticated electronic aids that accomplish essentially the same results, on the other hand?

Subject to further refinement of what outcomes are truly comparable, we believe that this research, coupled with the previously proposed study, could assist and induce the insurance industry to fundamentally rethink its approach to medical necessity as that concept bears on a variety of goods and services that people with disabilities now need and that more and more people will want and need as time goes on.

j. MENTAL HEALTH PARITY

While insurers and others have concerns about the potential costs of requiring mental health benefits and services to be available on terms of equality with benefits for physical diagnoses, other factors also may play a role in the resistance to mental health parity. Many factors suggest the persistence of deep-seated prejudice against people with mental illness, and psychiatric

survivors continue to be greeted with fear and suspicion in many quarters. NCD has documented many of these experiences and concerns in a series of reports.[74]

From the standpoint of the available evidence, the burden of proof on the question of the costs of mental health parity should properly lie with those who claim that the costs of parity are prohibitive. Moreover, with the increasing recognition of the interconnection between mental, emotional, and underlying biochemical, hormonal, and other somatic factors, the distinction between mental and physical illness is itself being called increasingly into question. That distinction is further eroded by the growing use of drugs that act to influence behavior or affect in exclusively biochemical ways, through inhibiting or stimulating various enzymes, neurotransmitters, peptides, amino acids, and other chemical messengers and pathways. Similarly, the role of organic factors in phenomena ranging from personality change resulting from trauma, to lethargy resulting from stress-mediated adrenal exhaustion, to dementia associated with hardening of the arteries have become widely recognized and understood.

All indications are that the dichotomy between mind and body will continue to disappear with new discoveries and treatments. In light of such findings and prospects, what is the relevance of disease names when the mode of treatment for many of those denominated as mental and those denominated as physical is becoming more and more alike and when the role of psychological factors in ostensibly physical disease and the role of physical factors in supposedly mental conditions are becoming increasingly clear and significant?

NCD believes the time has come to establish mental health parity in the patients' bill of rights or in separate legislation.

2. AMERICA'S LAW ENFORCEMENT AND MENTAL HEALTH PROJECT

As discussed in last year's report, America's Law Enforcement and Mental Health Project was enacted in 2000.[75] Among other things, the law authorized the attorney general to make grants to

state and local governments to establish demonstration judicial diversion programs, also known as pretrial diversion, that involve (1) continuing judicial supervision, including periodic review, of preliminarily qualified offenders with mental illness, mental retardation, or co-occurring mental illness and substance abuse disorders who are charged with misdemeanors or other nonviolent offenses; and (2) the coordinated delivery of services to these individuals and to the justice system, including specialized training of law enforcement and judicial personnel to identify and address the unique needs of a mentally ill or mentally retarded offender; voluntary outpatient or inpatient mental health treatment in the least restrictive manner appropriate, as determined by the court, that carries with it the possibility of dismissal of charges or reduced sentencing on successful completion of treatment; centralized case management, involving the consolidation of all of a mentally ill or mentally retarded defendant's cases (including violations of probation) and the coordination of all mental health treatment plans and social services; continuing supervision of treatment plan compliance for a term not to exceed the maximum allowable sentence or probation period for the charged or relevant offense; and continuity of psychiatric care at the end of the supervision period.

In its 1999-2000 annual report, NCD recounted hearing from a number of individuals with psychiatric disabilities who belong to leadership organizations representing millions of psychiatric survivors. These individuals and groups expressed profound concern and fear that once an offender with psychiatric disability enters a diversion program, he or she would be judicially required to abide by the mental health treatment program ordered by a case manager, probation officer, or even a prosecutor under threat of being judged in violation of the terms of the program, even if the mandated treatment is harmful or debilitating (as, for example, electroconvulsive therapy) and even if the treatment later proves to be inappropriate.

Such coercive outcomes would be inconsistent with the findings and recommendations of NCD's 1999 report *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*, which underscored the inappropriateness and harmfulness of forced mental health treatments. Because of these concerns and other issues regarding the "voluntariness" of

participation by individuals with cognitive or psychiatric disabilities in the mental health court system, NCD recommended that the DOJ establish mechanisms for consulting with people who are psychiatric survivors in the implementation of the law.

At this time, *NCD recommends that the DOJ issue an overview and update on the implementation and early results of this important new law, with particular attention to the concerns reiterated above, but also with a view to fostering the emerging dialogue over the proper interplay between the criminal justice and mental health systems.*

3. PAIN RELIEF PROMOTION VERSUS ASSISTED SUICIDE

In last year's report, NCD discussed the proposed Pain Relief Promotion Act of 2000,[76] which was intended to permit the use of controlled substances to relieve pain or discomfort. The bill was not adopted into law. Recent action by the attorney general aimed at preventing implementation of Oregon's Death with Dignity Act has brought the subject of "assisted suicide" back to the forefront of public consciousness.

NCD believes that responsible and compassionate pain relief should be a right of all people, but provisions to guarantee this right must be implemented in a manner that protects people with disabilities, who may be more vulnerable than other people to the risks and dangers of assisted suicide (or even undetected homicide) in the name of unregulated pain management. NCD has articulated its position in this regard in its report *Assisted Suicide: A Disability Perspective*.[77] NCD again cautions the Administration and Congress to recognize the potential dangers of crafting a federal law that promotes pain management without protecting the human rights of people with disabilities. But NCD also believes that appropriately regulated access to pain management, not only through medication—whether with controlled or noncontrolled substances—but through a variety of other modalities ranging from biofeedback and acupuncture to support groups and visualization, constitutes a humane and essential component of medical care and societal responsibility.

Accordingly, *NCD recommends that the Bush Administration and Congress create a national commission, composed of leading experts from the fields of law, medicine, and bioethics and including representatives of the disability community, to develop a framework for legislation that will adequately address the ultimately inseparable rights to life and to life with dignity.* In this connection, NCD reminds the Administration and Congress that the despair undoubtedly experienced by some people with disabilities and the willingness to end their lives that some may feel are often the results of discrimination, prejudice, and barriers that many people with disabilities continue to encounter. Too often, the restrictions and lack of options that this society has imposed, rather than people's disabilities or their physical pain, cause some lives to be unsatisfactory to the point where ending them becomes a conceivable option. From the standpoint of preserving life, attention devoted to these basic truths may do more to prevent unnecessary and untimely forfeiture of precious life than any measures to control the activities of doctors or to restrict the availability of dangerous drugs could ever hope to accomplish.

4. MEDICARE

NCD commends the Centers for Medicare and Medicaid Services (CMS), formerly the Health Care Financing Administration (HCFA), for its decision early this year to remove the restriction against coverage under the program of augmentative communication (AAC) devices.[78] The manner in which this reform came about contains valuable lessons for other steps CMS could take, both in its administration of the Medicare program and in its oversight and monitoring of state administration of the Medicaid program.

The now-rescinded coverage exclusion on use of Medicare funds to pay for AAC devices stemmed not from the law but from a national coverage decision adopted many years ago by the administrative agency in accordance with its broad statutory authority to interpret and apply the law. In other words, the ban was wholly an artifact of regulations. The Medicare statute in no way purported to deny AAC devices where they were appropriate or necessary, but the statute

also vested the implementing agency, as the complexity of the law makes necessary, with vast discretion over every aspect of the program.

Like the former AAC national coverage decision, the Medicare program includes in the accretion of rules and regulations that have marked its growth over more than a generation a potentially enormous number of other barriers to function by people with disabilities, barriers that may once have been justified but no longer comport with our available technology or growing understanding and barriers whose origins and initial rationale may even be lost to time and memory. Although some of these barriers (including those posed by local as well as by national coverage decisions) may on re-examination prove defensible, many others will not.

NCD recommends that CMS convene a panel of experts, health care practitioners, and beneficiaries, including persons receiving Medicare by reason of their status as SSDI recipients, to broadly review the entire range of existing limitations on coverage and to make recommendations concerning changes that would advance the purposes of the program and that would eliminate undue and often arbitrary distinctions between what is and what is not compensable. This review should include national and regional coverage decisions, regulations, manuals, and all other sources of administrative input into the content of the law.

5. TELEMEDICINE

Broadly speaking, telemedicine involves diagnosis, treatment, or monitoring done remotely through the use of a variety of devices linked through the telecommunications system. But as with any new organizing principle or technology, telemedicine is creating its share of new problems, even as it bids to solve old ones.

For many people with disabilities who do not travel with the ease or regularity they might wish, telemedicine constitutes a particularly appealing resource. But few if any reimbursement systems or funding streams have undertaken a comprehensive assessment of what changes in their

payment criteria or fee schedules are needed in order to make telemedicine work, while preventing its becoming a dehumanizing and impersonal force. To illustrate, there may be instances in which energetic deployment of telemedicine technology could pay for all or part of itself through concomitant reductions in the cost of medical transportation or personal assistant services. The effective use of such modalities, however, requires attention to infrastructure costs (including, for example, the installation of appropriate broadband telephone service) that have never before been on the medical system's reimbursement radar screen.

For people with disabilities, successful implementation of telemedicine's potential also requires attention to some very distinctive issues that may not be apparent to anyone who does not have a disability. Consider what is involved in maintaining many monitoring devices. If an individual lacks the physical dexterity to perform the required tasks, if the person lacks the visual acuity to see a light go on or to monitor a digital readout, or if a person lacks the hearing to discern an audio alarm, the potential of telemedicine may be compromised. NCD finds little indication that the technology of telemedicine is being developed with the needs of or usage by people with disabilities in mind. As with so much medical technology, whereas the interests of clinicians and manufacturers may receive considerable attention, no systematic means for obtaining consumer and end-user input may exist, and in a market dominated by third-party payers, to the extent payment is forthcoming at all, consideration of the desires of end-users is likely to receive little attention or weight.

As telemedicine proceeds, its development must proceed with attention to the human assistance and accessibility needs of those it is intended to benefit, as well as to its accessibility and usability by health care workers with disabilities. Because telemedicine does not yet have a large installed base, time is still available to remedy these omissions and to ensure that the evolving system is designed with all these users and concerns in mind. To wait longer may be to leave the matter for too long. Congress should hold hearings on the changes to the insurance system, particularly to Medicare and Medicaid, which are governed by federal law, that would be required to make telemedicine work, as well as on the accessible design requirements that would

be needed to ensure that the technology of telemedicine can be effectively used by those for whom it could make the greatest difference and whose care costs it could most dramatically reduce.

Chapter 5

Long-Terms Services and Supports

As our population ages, the costs and alternatives for community living, long-term care, and support services have become a subject of growing attention and concern. For many people with disabilities, including persons living in institutions because of the lack of community-based or in-home alternatives and those at risk of entering institutional care settings against their will, the issues take on pressing personal significance.

With the Supreme Court's historic 1999 decision in *Olmstead v. L. C,*[79] the context and imperatives for public policy in the long-term care arena have been irrevocably changed. *Olmstead* gave new weight and meaning to the provisions of Title II of the ADA, which requires public services, including Medicaid-funded long-term care, to be provided in the most integrated settings possible. Now, unnecessary institutionalization of people with disabilities is illegal.

The Bush Administration has recognized that effective community-based services involve the coordinated efforts of a number of federal agencies, as well as of state government, and the Administration has moved forward on measures to bring such coordination about and to facilitate the development and implementation of plans to make the principles of *Olmstead* a reality.

1. THE ADMINISTRATION RESPONSE

In June 2001, following intense advocacy efforts by and on behalf of the disability community, President Bush issued Executive Order 13217. Among other things, the order required designated federal agencies with responsibility and jurisdiction in the long-term services area to conduct self-evaluations designed to identify barriers to community living in their regulations, practices, and areas of concern. The major agencies involved were the Department of Education (ED), the Department of Health and Human Services (HHS), the Department of Housing and Urban Development (HUD), the Department of Justice (DOJ), the Department of Labor (DOL), and the

Social Security Administration (SSA). Several offices and administrations within these agencies were also expressly involved, and several other departments, including the Department of Veterans Affairs (VA) and the Department of Agriculture (USDA), also figured in the findings and recommendations set forth in the preliminary report on the self-evaluation effort. This preliminary report, *Delivering on the Promise*,[80] was released by HHS on December 21, 2001. It sets forth a variety of policy initiatives, action proposals, and goals that will be pursued in the coming year and beyond.

NCD submitted comments to the Office of Management and Budget (OMB), which will be reiterated as applicable here.

Two structural features of the self-evaluation process appear key to the success of any such endeavor: first, the appointment of a lead agency (in this case HHS) to receive and synthesize all agency reports and to compile and publish them in a preliminary report reflecting the entire effort; second, the establishment of the Inter-agency Committee on Community Living (ICCL). *NCD recommends that as the federal* Olmstead *initiative moves from research to implementation of key recommendations and findings, these two structural components be fully institutionalized.* Only through use of a lead agency can accountability for the overall effort be established and ensured.

It may be that the Bush Administration will choose to use the ICCL as the lead agency for *Olmstead* implementation. If so, this committee must be given the resources, visibility, and authority to effectively perform this role. Likewise, if a line agency such as HHS is designated, it too must be given the personnel, management, technical, coordination, and fiscal resources necessary to do the job. Given the pressing and often conflicting demands on the resources of the involved agencies, and given looming federal budgetary strictures, continued White House attention will be required if the promise referenced in the title of the Administration's report is to be kept.

As critical as are the continued commitment and coordination of all the involved federal agencies and the existence and support of administrative mechanisms to ensure the necessary coordination, accountability, and sustained follow-up, one key resource cannot come from within the Federal Government. That resource is the knowledge and experience of other stakeholders, including service providers and, above all, persons with disabilities themselves, in gathering resources, monitoring progress, and identifying priorities for the effort. Accordingly, the administrative structure developed for continuing the *Olmstead* momentum must include means for obtaining and incorporating the regular input of those who know the issues best and whose lives will be most affected by the results.

Apart from effective interagency coordination and the fullest possible participation by pertinent nongovernmental individuals and organizations, other conditions must also be met if the *Olmstead* initiative is to succeed. Although we recognize that the report is preliminary, its omission of any discussion of time lines is a matter of concern. In the absence of time lines for the completion of tasks and the carrying out of activities, accountability becomes difficult if not impossible to assign. NCD trusts that in its next *Olmstead* planning document, the Administration will address the question of how much time is required to accomplish the myriad tasks requisite to success and specify measurable and accountable time frames consistent with these assessments.

Establishment of time frames serves another valuable purpose as well. Because coordinated action is required on the part of many agencies, time frames and schedules can provide the basis for ensuring that things that need to be done in tandem and things that need to be done in sequence can be scheduled or sequenced to achieve the maximum results anticipated for them. For example, the HHS report includes a number of initiatives on HUD's part that will prove critical to the community living effort. If the timing of measures to make sufficient, affordable, and accessible housing available is not adequately synchronized with the timing of measures that remove people from institutions or prevent their entering them, serious incongruities and

discontinuities will be created. Only realistic scheduling, sufficient allocation of resources, and disciplined adherence can ensure that this does not happen.

In this connection, *NCD also recommends that in subsequent planning and progress reports, the Administration emphasize the interconnectedness of each agency's measures.* The HHS report does an excellent job of laying out a variety of measures that each involved agency can take, but some measures involve joint action or require the development of complementary or reciprocal regulatory changes.

2. MAJOR PREMISES OF THE REPORT

To evaluate what the Administration has found and what it proposes to do, some discussion is needed of what appear to be the major premises underlying the approach reflected in the HHS report. Some of these premises are likely to meet with almost universal approval from the disability community and other stakeholders. Others may give rise to some debate and discussion.

Two facts underlie the philosophical and policy premises of the government's *Olmstead* initiative. First, as stated in the HHS's report, some 73 percent of Medicaid long-term care resources currently go to institutional care and some 64 percent of home care is provided by unpaid family caregivers, friends, or neighbors. The report recognizes the economic and emotional toll this takes on the caregivers and includes a number of recommendations—ranging from increasing the pool and professionalism of paid home and community service workers to providing respite and other support services for these unpaid caregivers—for easing these burdens.

The second key fact, as the very existence of the *Olmstead* initiative demonstrates and as the report makes clear, is that the Administration believes in the principles of community living and maximum possible integration that underscore the ADA and that lie at the heart of

deinstitutionalization efforts for successive populations over the past two decades. In its operationalization of this belief, the Administration recognizes the existence of several types of living arrangements within the framework of a community-based setting. While we naturally think of a person's home as the preferred place for an individual to live, other options—including intermediate care facilities for persons with mental retardation (ICFMRs), assisted living facilities, and board and care homes—are also acknowledged as worthy of support (such as by the VA) in certain instances.

NCD shares the recognition that the ideal of enabling everyone to remain in his or her own home is a major challenge. But NCD believes that the Administration must remain mindful of the existence of a hierarchy of community-based options, with the home first and other facilities and settings following when the home is not feasible or the individual opts for one of these other settings. NCD hopes that all programs developed under the *Olmstead* initiative will keep this hierarchy in mind and will use procedures and criteria that give maximum effect to the wishes and preferences of the individuals being served.

The initiatives gathered in the report reflect substantial dependence on states to make the *Olmstead* initiative a success. Given the structure of the Medicaid program, with the principal role played by states in its implementation, this dependence is to be expected. A variety of measures are proposed for empowering the states in this area, ranging from further easing of Medicaid waiver requirements to additional *Olmstead* planning grants to technical assistance to the states. But beyond specific grants and certain changes in the rules governing Medicaid coverage, including the heightened availability of home and community-based waivers (HCBW), the report recommends no fundamental restructuring of the Medicaid reimbursement system, including changes of the sort that would reward states for success in meeting qualitative or numerical *Olmstead* goals. Nor does it appear that any relaxation of state matching fund requirements under the Medicaid program is yet contemplated.

Whereas NCD believes that effective federal-state partnerships are essential to the success of this effort, and whereas we welcome the opportunities for variety and experimentation that the active participation of the states portends, we are concerned that states will be expected to make new financial commitments at a time when, no matter their support for the principles of *Olmstead*, they may find it difficult to do so. NCD would not regard exempting states from financial participation in implementing the *Olmstead* agenda as either prudent or feasible.

In this regard too, it must be borne in mind that the nursing home industry and other institution-based human service providers are reputed to be politically powerful in a number of states. In such states, the objections to any significant moves in the direction of community-based services and care, and the industry's fearfulness of the diversion of any substantial proportion of long-term care funds from institutional to community care, could further complicate the efforts of states to wholeheartedly embrace the *Olmstead* agenda. The Administration is urged to be alert to this possibility as well and, if necessary, to look for means for offsetting these counterbalancing effects.

3. THE ECONOMICS OF *OLMSTEAD*

Broadly speaking, two ways exist to fund any major new initiative: Funding streams can be diverted from other uses or new funds can be brought to bear. The HHS proposal appears to propose some of each, but whether the freed-up or added aggregate sums will be sufficient depends on the numbers of current or potential nursing home residents intended to be moved into community-based settings and on the costs of such relocation. The report offers no estimate of the amount of money that would be generated or diverted by the steps it proposes. As significant, although we recognize the prematurity of hard and fast budgetary projections, the absence from the report of any estimates regarding the costs and savings of implementing *Olmstead* (or of the net costs after resultant savings are taken into account), as well as the absence of any discussion of a methodology for comprehensively tracking these benefits and costs, cannot but be cause for concern.

Although the long-term fiscal implications of the *Olmstead* initiative will, we believe, prove far less onerous than they may at first appear, up-front costs will without question need to be anticipated and met. With a federal budgetary environment radically different from that which prevailed at the time *Olmstead* was decided only three short years ago, the question of how these costs will be met poses serious issues. It therefore seems reasonable to suppose that only with massive redirection of funds from current expenditure patterns can the nation and its citizens with disabilities hold out any reasonable hope of the promise of *Olmstead* being kept in the foreseeable future.

With 64 percent of current long-term care funds and 75 percent of Medicaid funds going into institutional care, a potential source for such funding is not difficult to identify, but the difficulties of massive redirection of funds and reformation of policy are complex by any standard. Not only leadership but great courage and wisdom will be required for the Administration and Congress to bring this about. NCD and the disability community stand ready to be of all possible assistance in this effort.

Lest policymakers be prone to follow the path of least resistance and to seek to avoid uprooting powerful entrenched interests or long-established habits and patterns, the public debate surrounding the Laguna Hospital case in San Francisco should be viewed as a harbinger of developments likely to occur elsewhere in the country.[81] Following the announcement of a plan to expend nearly a half billion dollars on a massive institutional rebuilding project, people with disabilities and advocates joined together to demand the redirection of these funds to community living and related services. On December 18, 2001, the U.S. District Court for the Northern District of California, relying on the *Olmstead* precedent, for the second time denied motions by the state and city defendants for the dismissal of the class action lawsuit filed to block the Laguna Honda building project. It is interesting that plaintiffs' legal counsel in the case included not only disability advocates but representatives of senior citizens as well.

As prophetic as community opposition to this major bricks-and-mortar project may be, and as portentous as is the emergence of an alliance between people with disabilities and senior citizens around the goal of community living, the apparent intransigence of the state and municipal authorities in the matter may be of even greater significance. Such intransigence may illustrate, as vividly as anything can, that only with strong and continuous federal oversight, support, and suasion can the words of *Olmstead* be turned into the reality of daily life for so many.

4. OTHER PROGRAMMATIC ISSUES

Whatever numerical values are ultimately applied to the process, success of the *Olmstead* initiative depends on the following: returning to the community the largest number possible of currently institutionalized persons who wish to live in community-based settings; ensuring that these persons are returned to their homes where possible or to the least restrictive, most integrated group settings where not possible; preventing the institutionalization of as large a number of at-risk persons as possible; identifying and providing the resources, program supports, and infrastructural elements necessary to maximize the likelihood of success in working with or on behalf of each individual; and developing the most active and effective range of intergovernmental, federal-state, for-profit, and nonprofit private-public partnerships in the service of the effort. This agenda is large and can only be operationalized and addressed over time. But a number of structural features of the Medicaid program, though not addressed in the HHS preliminary report, are likely to create barriers at an early stage and thus are worthy of anticipation and discussion here.

Although means-tested and directed at people of limited economic means, the Medicaid program has become a support of surprising importance to many middle-class Americans. The "spend-down" provisions of the law are one of the main reasons this is so. Through the use of spend-downs and related provisions, people whose means are initially too great to qualify for Medicaid, but too small to sustain the costs of long-term institutional nursing home care, have been allowed

or forced to use their own resources to the point where those resources (subject to certain statutory exceptions) are exhausted, and then to qualify for Medicaid.

For persons avoiding or delaying nursing home care through participation in the *Olmstead* program, the costs of adequate community-based care or home services will still exceed and deplete the resources of many initially middle-class people in many instances. Spend-down provisions will need to be expanded and modified to allow at-risk individuals to benefit from the *Olmstead* initiative, in much the same way, save for place of residence, as those provisions now facilitate the support of institutionalized persons. The HHS report appears to recognize this fact, but a number of the key issues remain to be addressed.

In a related vein, to the degree that additional public and private funding streams will need to be joined with Medicaid to amass the resources needed to keep the *Olmstead* promise, attention will need to be paid to coordination of benefits and to potential inconsistencies and contradictions between the rules applicable to these other programs and to the rules governing Medicaid. Bearing in mind the pressing demands that already exist on their resources, funding streams that should be considered and integrated where appropriate include the following: Older Americans Act funds, community development block grant (CDBG) funds, independent living funds, and, where they exist and are still funded, state in-home services programs. In addition, *NCD recommends that the Administration support and Congress enact two statutes that have been proposed in recent sessions: the Family Opportunity Act and the Medicaid Attendant Services and Support Act (MiCASSA).*

5. IMPLICATIONS FOR THE NON-MEDICAID POPULATION

In the long run, the availability of long-term services and supports to enable people with disabilities to remain in their homes and to enable older people to age in place is an issue for our entire population. The issue is not limited to those who receive or even who could conceivably become eligible to receive Medicaid. For us to truly reverse the pro-institutional bias inherent to

greater or less degree in most of our funding and service systems, modifying the costs and benefits applicable to a variety of stakeholders will be necessary. One element of this involves our nation's need to dramatically increase the availability and affordability of private sector long-term care insurance. As important, we need to modify the current balance of incentives and disincentives under which insurers operate, so that home care will become the preferred option to institutionalization for insured and insurer alike.

Currently, when affordable long-term care coverage is available, it frequently tips the scales in favor of nursing home admission and residence by providing substantially higher rates of reimbursement for institutional care, by offering only inadequate amounts for in-home services and supports, by imposing conditions on payment for in-home care (such as number of activities of daily living compromised or level of medically determinable illness) that further limit the availability of reimbursement, and by a number of other restrictive provisions and practices. This annual status report is not the place for presenting detailed recommendations about how these patterns could be changed or about what kinds of public-private partnerships might be effective in making long-term care insurance readily available. It is enough to observe that the need is too great for government to possibly meet alone, but if the need is not met, our nation faces risks of intergenerational conflict too disquieting to willingly contemplate or ever permit. NCD will continue to lend its experience, its access to people with disabilities, and its good offices to this unfolding public discussion in the months and years to come.

6. SOCIAL SECURITY REFORM

For a number of years, the solvency of the Social Security retirement system has been a subject of discussion and growing public apprehension, particularly among younger workers who fear that the system will not be there for them when their turn to retire comes. With the appointment and recent report of the Presidential Commission on Social Security Reform, the questions surrounding the future of Social Security, including the possibility of its partial "privatization," have come even more to the fore.

What is striking, though, is the absence from the commission's charter of any attention to the disability insurance (SSDI) program or to the possible impact on the SSDI program of any proposed reforms. Some people have expressed concern that some of the measures under consideration by the commission could adversely effect the SSDI program.

Our purpose here is not to evaluate these risks or to propose reforms in the funding or administration of SSDI. Nor do we hope to opine on the various official assessments of the health and solvency of the SSDI trust fund. But NCD does feel obliged to remind the Administration, Congress, and the public that Social Security (under the Old-Age and Survivors component of the program for retirees with disabilities and for younger persons receiving benefits under the SSDI program) is a matter of great concern and importance to many Americans with disabilities. It may be that different trust funds and different demographic projections are involved; however, we believe it is dangerous and short-sighted to consider any major changes in any part of the Social Security system without taking their potential impact on all recipients carefully into account. Nor is it possible, because Social Security in one form or another is among the major funding streams for many people with disabilities and many older Americans, to analyze and unravel the complexities of *Olmstead* implementation without taking the availability and role of these funds into account as well.

Accordingly, *NCD recommends that the charge to the present and to any future commissions be expanded to include consideration of the SSDI program, and that all major proposals for restructuring any part of the Social Security system be prepared with the interests, testimony, and statistics of recipients/beneficiaries with disabilities in mind.* Otherwise, the fragmentation, inconsistency, and even contradictory patterns of past policy are not likely to be remedied any time soon.

Chapter 6
Issues of Special Concern to Youth

Most of the sections of this report apply to everyone, youth along with adults. Issues of health care, housing, and long-term services bear on the lives of children and young adults with disabilities as much or in some cases with more weight than they affect the lives of older persons. Beyond the issues that affect everyone, a number of issues are of specific concern to youth and young adults with disabilities and therefore warrant inclusion in a separate chapter dealing with this segment of the population.

1. SCHOOL TO WORK TRANSITION SERVICES

As documented by NCD's research[82] and as recently acknowledged in the HHS Olmstead federal agency self-evaluation report discussed in chapter 5, the secondary school outcomes for youth and young adults with disabilities remain dramatically inferior to those achieved by their peers. Perhaps the most troubling statistic in this saga is the academic graduation rate, which for students who have received special education services hovers at around 27 percent, compared to 75 percent for students without disabilities. Thus slowed at the starting line, continuing disparities in postschool life would not be at all surprising.

Facing an economy in which entry-level jobs are likely to be harder to come by and where youth unemployment is likely to rise, the consequences of what does or does not happen in school are likely to be more influential more quickly than they may have been in recent years, when demand for workers of all kinds, including entry-level workers and recent graduates, stood at the highest levels since World War II. Ironically, even certain long overdue reforms in the policies of the vocational rehabilitation (VR) system may have made the transition of some students with disabilities from school to adult settings that much more difficult. In 2001, the Rehabilitation Services Administration (RSA) issued regulations implementing the Rehabilitation Act Amendments of 1998..

For these reasons and others, effective transitional services are more crucial today than they have perhaps ever been before. In this light, the issues surrounding transition and the barriers to its success, though among the most chronic source of frustration facing successive administrations and the disability community, warrants further discussion and innovative approaches. The forthcoming reauthorization of IDEA is the logical time and place for doing this.

Last year's NCD status report reviewed a number of initiatives undertaken during 2000 to begin remedying the transition situation. As last year's report stated, these efforts laid a foundation that requires further building in the form of effective systems at federal, state, and local levels. One of the most far-reaching of these initiatives was the release by the Social Security Administration (SSA) and NCD of a joint report calling attention to persistent issues and problems documented in national postschool studies.[83] While postsecondary education participation showed slight improvement, more youth with disabilities found themselves unable to enter employment on leaving school and ended up consigned to Social Security benefit rolls. The data in this report made clear that, shocking and unacceptable as low academic graduation rates are, these disparities do not by themselves explain the employment and related life outcomes disclosed by the study. That possession of a regular high school diploma highly correlates with lifetime earnings potential is well-known. But other factors go into the equation as well.

One of these might be the availability or unavailability of early work opportunities. In this connection, the report indicated that youth with disabilities who had participated in vocational or other on-the-job training opportunities were less likely to cease work and return to the SSDI rolls than were older disability insurance beneficiaries.

In their efforts to enter the employment mainstream, young people from diverse cultural groups, the report found, faced additional barriers, such as lack of attention to their limited English-language proficiency, use by service providers of culturally inappropriate strategies or information, and insensitive service providers. Finally, the report identified strategies that have

worked and that should work, in light of existing legislation, unmet needs, and unserved populations, and it presented recommendations for national, state, and local community action.

One of the best strategies identified for improving the quality of post-school outcomes is effective and coordinated transitional services. Under IDEA, the responsibility of schools to students receiving special education services is not limited to what happens to them while they are in school. Likewise, under the federal Rehabilitation Act, the obligation of the VR system for individuals with disabilities does not begin the day the schoolhouse door closes behind them for the last time. Through the vehicle of transition services, both service systems are responsible for coordinated planning and programming during the final years of school to ensure that students with disabilities have the skills, experience, and technology they will need to successfully enter the postschool world and to facilitate as smooth and seamless a transition as possible from educational to adult services.

Whereas many local examples of effective and cooperative transition planning can be found, the institutional barriers, jurisdictional lines, cost-shifting agendas, and lack of accountability that broadly characterize the transition process have combined to create one of the most long-standing and intractable obstacles to successful entry into employment or other postsecondary educational activities for many young people with disabilities. Accordingly, *NCD has strongly recommended and continues to urge that the Administration and Congress develop an overarching focus on the kinds of communication, collaboration, and accountability that exist across all federal agencies and programs that need to be involved in preparing our nation's young people with disabilities for full participation in society.*

These efforts need to begin with dialogue among the affected parties, especially including youth with disabilities themselves. Collaboration must extend not only to such specialized service systems as VR and special education, but also to the broader workforce development systems such as one-stop centers and workforce investment boards operated under the Workforce Investment Act of 1998 (WIA), Job Corps, apprenticeship training programs, Americorps,

general equivalency diploma (GED) degree programs, vocational education programs, community college systems, and others.

With both IDEA and the Rehabilitation Act coming due for reauthorization, and because they are the logical programs with which any new effort to improve transition services should begin, the time is right for serious new efforts to ensure that transition services will be provided effectively. As currently written, neither of these laws is lacking in provisions, indeed in mandates, for transition planning and services, but what does appear to be lacking are adequate provisions that link the operation of the two statutes and that provide for joint accountability on the part of the special education and VR systems.

a. ASSISTIVE TECHNOLOGY

One problem that frequently hinders effective services is the need for transitioning students to obtain assistive technology (AT) for use in postsecondary settings. Apparently, students are caught between the schools' desire to retain ownership of AT they have purchased, on the one hand, and the VR system's reluctance to buy new, often duplicate, AT, on the other hand, particularly its unwillingness to buy duplicate or additional equipment while the student is still in school.

A solution to this problem could be at hand that would not require VR agencies to purchase duplicate technology to what the student has been using in school. The Federal Government should provide guidance and technical assistance to ensure that both educational and rehabilitation agencies are aware of means for transferring ownership of such technology from the one system to the other. Specifically, *the IDEA reauthorization and the forthcoming VR act amendments should both include clear and unambiguous language requiring states to eliminate from their laws any provisions that would prevent or unreasonably complicate entry by educational and rehabilitation agencies into repurchase or other transfer agreements that would*

allow appropriate AT to follow the student where the school system has no present need for it and where the user does have a continuing need.

Similarly, *IDEA and the Rehabilitation Act should contain identical language clarifying the appropriateness of such transfers under federal law, indicating the value of such transfers as a means for expediting transition and minimizing costs, and setting forth a number of models (from among those that already exist around the country) for how the residual value of equipment can be determined, for how repurchase or transfer agreements can be structured, and for how auditing and monitoring procedures should work.* Using standard accounting procedures that take equipment's age and expected useful life into account, valuation and pricing of equipment to be transferred should not be difficult to determine.

b. COST-SHIFTING

Undoubtedly, one of the chief structural barriers to the delivery of effective transition services is the belief on the part of each service system that the other should pay. *NCD recommends that Congress articulate and legislate a clearer answer than currently exists, and incorporate that answer in both statutes.* Convincing arguments can be made on both sides of the case, but the current uncertainty, leading as it does to innumerable low-level disputes and redounding to the disadvantage of postsecondary students with disabilities who cannot be expected to mediate or resolve these disputes, cannot be justified or allowed to continue. Standards must be developed that clarify the financial responsibility of each service system in the transition process. Existing provisions governing the potential role of Medicaid (for students who are eligible for it) should also be clarified. The end result should be a set of arrangements, an allocation of financial responsibility, and an order of precedence that, although not increasing the costs of transition, will eliminate the inefficiencies and costs associated with the current belief of each involved service system that it is the payer of last resort.

Lest cooperation between these entrenched systems be deemed impractical, it should be remembered that both special education and vocational rehabilitation are administered and supervised by a single cabinet department, the Department of Education. Given this commonality, the reauthorizations could instruct the secretary of education to establish administrative review procedures for quickly and definitively resolving disputes between the two service systems regarding the proper allocation of costs or other aspects of their roles and relationship under the law. It is surely not unreasonable to expect that programs administered by a single federal agency be able, or be made, to work effectively together, or that the oversight agency be expected to resolve disputes between recipients of federal funds under the programs it administers and monitors.

As it too often plays out now, students and other youth suffer as service systems battle to shift costs, and this situation is not necessarily limited to special education and VR or college administrators and VR. With the complexities of the law, it is hardly reasonable to expect students or young labor market entrants to be able to determine, let alone enforce, answers to these questions.

One approach to the cost-shifting problem involves implementation of a right-of-recovery approach. Under such a pay-first-fight-it-out-later approach, if either of the agency partners failed or refused to fulfill its responsibilities under the law, the other would provide the necessary services, pay the required sums, and seek recovery later. Whereas this approach could act as a deterrent to cost-shifting if the noncompliant service provider were financially penalized for its failure to perform, there is no guarantee that an agency that thought it could escape punishment would still not consider the potential punishment worth risking. In light of historical experience, the chances of state agencies being financially penalized by the Federal Government for failure to meet the requirements of either the special education or vocational rehabilitation laws must be regarded as small. Moreover, such a system would still require the student or youth with a disability to act as more of his or her own case manager than is reasonable to expect. Under these

circumstances, only an approach that imposes joint financial responsibility for success or failure, and that is not discretionary, will suffice to enforce the necessary coordination.

c. JOINT ACCOUNTABILITY PILOT PROJECT

Too often, joint- or multiple-agency responsibility in law amounts to no responsibility in fact. If two entities are responsible for some action or outcome, how are their relative roles in success or failure to be evaluated, especially if they disagree on the key facts? This is the problem that further complicates and frustrates efforts to monitor transitional services. No one has the authority to lay blame and, as significant, no penalties or other costs have attached to any of the involved service systems for failure. But when both service systems succeed in avoiding the responsibility to pay or to bring about the desired outcome, this hardly means there are no costs. Those costs all too frequently become the responsibility of the Social Security system or of other income-maintenance programs.

In the end, blame may be of little more use than mandates. Instead, a bold and innovative approach is necessary that offers incentives for cross-agency transitional efforts and that rewards or sanctions the agencies in tandem, depending on the outcome. To accomplish this, Congress should establish a pilot program using competitive grants to VR agency-school district consortia. The amount of funding ultimately forthcoming should depend on the achievement of measurable, objective, and predetermined outcomes relating to evidence of success in the delivery of transition services and relating to the involvement and satisfaction of youth with disabilities. Models for such funding approaches exist under a number of laws, including the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA), which compensates Employment Networks on the basis of their achievement of various milestones in their work with Social Security recipients.

Appropriate milestones for use of such an approach in the transitional services sphere might include participation of both agencies in planning meetings; establishment of joint transition

plans on behalf of specified numbers of students; provision of services and completion of steps called for under these joint plans; and achievement within expected time periods of the postsecondary school placements, employment, or other outcomes contemplated as plan goals.

Success would result in full funding. Failure would result in a pro rata, across-the-board reduction in funding, with both (or all) involved service systems forfeiting the same percentage of expected funds and, as important, with no room for finger pointing or blame-shifting. The service systems would succeed or fail, swim or sink, together.

For this approach at adding incentives to transition services to be successful, two things must happen. First, the parties to each pilot project must be able to develop, ideally with input from youth with disabilities and their families, predetermined, objective, and measurable outcomes whose achievement can be verified with a minimum of subjectivity. Second, in those cases in which these predetermined outcome goals are not achieved, the system must prove sufficiently robust to follow through on imposition of the specified financial penalties. If these criteria can be satisfied, consideration should be given to extending the approach to all participants in the transitional services process around the country.

d. CURRENT PROSPECTS

At the federal level, prospects for effective cross-agency, multiservice system cooperation seem better than they have been in some time. The spirit of the *Olmstead* implementation process embodies a recognition that our most pressing and intractable problems transcend agency lines or jurisdictional boundaries. NCD hopes that this spirit will extend to the provision of transitional services, not merely in the deinstitutionalization context of *Olmstead* but in the area of school-to-work transition as well, where interagency cooperation is badly needed and long overdue.

2. YOUTH LEADERSHIP NETWORK FOR YOUTH WITH DISABILITIES

As discussed in last year's report, the National Youth Leadership Network (YLN) was a five-year project involving the Departments of Education, Labor, and Health and Human Services, along with the SSA and NCD The project is research-oriented and designed to include annual leadership training for youth ages 16 through 24 with disabilities.

YLN conferences provide leadership training through discussions of ways young people can help the federal agencies to determine and update the impact of barriers to successful adult life; identify what works and what are promising practices; and highlight actions that should be implemented at the national, state, and local levels to incorporate and reflect the perspectives of youth with disabilities.

In last year's status report, NCD commended the line agencies for their foresight and sponsorship of this initiative. NCD also encouraged the Administration to support such recommendations for improvement that result from the evaluation component of this youth leadership project.

Amid the new initiatives coming out of the Administration, NCD believes it would be valuable for the Administration to review and comment on the status and results of the YLN initiative and its viability and, more broadly, to comment on its relevance to the New Freedom Initiative. In this context, we hope the Administration can further address the issues surrounding transition for youth with disabilities, including methods for identifying and targeting necessary specialized services, means for fully integrating youth with disabilities into the nation's employment training and placement systems, and ways for ensuring that economic trends and labor-demand forecasts will be appropriately used in the development of training programs, employment development, and job placement strategies.

3. EXPANDING EMPLOYMENT OPPORTUNITIES FOR YOUNG PEOPLE WITH DISABILITIES

At the outset, *NCD recommends that the Administration, through the Office of Disability Employment Policy (ODEP) or such other entities as may be deemed suitable, systematically review the technical assistance resources available to and needed by the various employment-related agencies and programs in order for them to adequately respond to the needs and aspirations of young people with disabilities.* Here we note that historically, increases in unemployment, such as our nation is now experiencing compared with the levels of the late 1990s, have their greatest impact on younger workers. If our nation undertakes measures to mitigate the disproportionate impact of reduced economic growth on youthful, often low-skilled entrants to the labor market, such measures must proceed with a recognition that among the futures at issue are those of many young people with disabilities. Therefore, any such national policy initiatives should take account of the barriers of discrimination, the need for AT, and other service and reasonable accommodation needs faced by these new workers.

Any such initiatives must also ensure that outreach and recruitment efforts encompass young workers and would-be workers with disabilities, and should ensure that materials, processes, and facilities are made accessible and culturally sensitive.

On October 25, 2000, former President Clinton signed an Executive Order[84] providing for improved access to employment and training for youth with disabilities. This Executive Order sought to improve employment outcomes for persons with disabilities by addressing, among other things, the education, transition, employment, health, rehabilitation, and independent living issues affecting young people with disabilities. Executive departments and agencies were tasked to coordinate and cooperate with the Presidential Task Force on Employment of Adults with Disabilities to strengthen interagency research, demonstration, and training activities relating to young people with disabilities; create a public awareness campaign focused on access to equal opportunity for young people with disabilities; promote the views of young people with

disabilities through collaboration with the youth councils authorized under the Workforce Investment Act; increase access to and use of health insurance and health care for young people with disabilities through the formalization of the federal Healthy and Ready to Work interagency council; increase participation by young people with disabilities in postsecondary education and training programs; and create a nationally representative youth advisory council, to be funded and chaired by the Department of Labor, to advise the Presidential Task Force in conducting these and other activities.

NCD recommends that the Administration indicate its views regarding the efficacy of these measures and indicate the appropriate structural arrangements for bringing these goals about. In this connection, the DOL recently awarded more than $11 million in grants to promote the New Freedom Initiative's commitment to integration of persons with disabilities into the employment mainstream of our nation.[85] NCD welcomes these initiatives and particularly commends the department for expressly including youth with disabilities in the scope of these efforts.

Along related lines, the Workforce Investment Act of 1998 (WIA), as just noted, created local workforce investment boards to guide the development of programs, to foster necessary connections and relationships, and to set priorities for program development and use of funds. Recognizing the special problems faced by youth in the competitive labor market, even in the good economic times that marked passage of the Act, the WIA created youth councils. *NCD recommends that the Administration, through ODEP or other appropriate entities, report on the status and function of these councils and indicate its views concerning their roles in future youth employment development efforts.*

Overall, *NCD recommends that the approach adopted by the Administration in orchestrating implementation of* Olmstead *could prove valuable in comprehensively identifying the barriers to training and employment faced by young persons and in developing interagency strategies for removing these barriers.*

Chapter 7
Employment

1. INTERAGENCY COORDINATION

The Office of Disability Employment Policy (ODEP), formerly the President's Committee on Employment of People with Disabilities, is now established within the Department of Labor (DOL), under the leadership of an assistant secretary. The office has a unique opportunity to bring coherence and accountability to the disability employment programs operated or funded under the auspices of the department, as well as to increase the awareness and responsiveness of mainstream employment development programs to the need for, and the issues involved in, making these programs accessible to all Americans seeking the dignity of work.

But commensurate with its opportunities, ODEP also faces major challenges if it is to succeed in its mission and avoid becoming just another set of initials on an organizational chart. Some of the specific program issues ODEP faces will be enumerated in this chapter. At the moment, it is enough to say that to be successful, the office will have to coordinate its work effectively, not only with other DOL units but also with other federal agencies and with the programs they administer. Some of the key coordinate agencies in other departments with which ODEP will need to work effectively are the vocational rehabilitation (VR) program administered by the Rehabilitation Services Administration (RSA) in the Department of Education (ED); the Employment Networks operating through the Social Security Administration (SSA) under the authority of the Ticket to Work and Work Incentives Improvement Act of 1999 (TWWIIA); the Office of Personnel Management (OPM); the Equal Employment Opportunity Commission (EEOC); and the Department of Justice (DOJ).

The issues are crosscutting. For example, efforts to substantially reduce levels of unemployment among persons with disabilities will require significant attention to basic skills training and to specific job and skills training opportunities that are keyed to the areas of labor shortage or

expected growth in labor market demand in our economy. Much of the responsibility and funding for this training rests with the state VR agencies operated under the federal-state VR program. Oversight responsibility for the state VR program rests with the RSA. As coequal agencies, a unit of the DOL has no authority to tell a unit of the ED what to do, but with coordination through the interagency committee and with other collaborative measures and relationships, it should prove possible for such entities as these two to identify and pursue common goals, to act jointly where appropriate, and to speak in unison to support any ameliorative legislation that might be necessary. Admittedly, such coordination between and among federal agencies, even among units of the same agency, has not been a hallmark of federal program administration over the years, but the creation and responsibilities of ODEP offer the opportunity for a new start.

The atmosphere of coordination and cooperation among cabinet-level departments that currently surrounds the *Olmstead* implementation efforts may contribute to the ability of diverse agencies and units, with different agendas, different cultures, and separate budgets, to work together in the identification and pursuit of common goals. NCD sincerely hopes that the momentum for cooperative and innovative responses to problems that are larger than any one agency or any single jurisdiction will continue to prevail and will mark and distinguish federal activities in the disability policy realm in the months and years to come.

2. BASELINE STATISTICS

As discussed in chapter 1, the absence of reliable statistical data on disability employment levels and employment trends represents a significant impediment to the forging of sound public policy. In last year's status report, NCD recommended that ODEP initiate and support the development and implementation of a measurement system that tracks and reports on the employment status of Americans with disabilities on at least an annual basis. Collaboration with the Bureau of the Census in its efforts to improve disability-related information collection in the

Current Population Survey (CPS) represents one way of bringing this important initiative to fruition and represents one useful approach to improving current data collection instruments.

More immediately, the HHS *Olmstead* preliminary implementation report *Keeping The Promise*[86] reports on parallel efforts to refine employment data collection undertaken by ODEP's coordinate DOL agency, the Bureau of Labor Statistics (BLS). The ability to bring these entities and other interested parties within the government together represents another excellent test case for cooperation and coordination in the pursuit of shared objectives and in the effort to meet common needs.

In connection with the problems posed by questionable employment statistics, *NCD recommends that ODEP work to ensure that all DOL units review their current research-funded grants and contracts to make certain that federal funding is not provided to support the production of research reports regarding employment of people with disabilities that rely exclusively on the Survey of Income and Program Participation (SIPP) or the CPS or other federal statistical sources containing major shortcomings.*

3. TICKET TO WORK AND WORK INCENTIVES IMPROVEMENT ACT

a. WORK INCENTIVES

TWWIIA[87] was produced through the combined efforts of the Clinton Administration, Congress, and the disability community. On December 17, 1999, it became the last major piece of federal legislation signed into law in the twentieth century.

TWWIIA consists of two distinctive but closely intertwined parts. First, by creating new entities for providing job-training and job-seeking assistance to individuals with disabilities who receive Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) benefits, and by creating financial incentives for success on the part of the Employment Networks

administering the "Ticket," the law created new methods and new resources for job training, job seeking, and job placement. Through its use of tickets (in effect, vouchers) issued to eligible individuals with disabilities for use by them in obtaining employment services from eligible Employment Networks of their choice, the law gave job seekers and employment service recipients unprecedented autonomy in selecting their own services and service providers.

The second major thrust of TWWIIA, beyond strengthening and energizing employment-related resources, is that the work incentives portion of the law attempts to reduce one of the major barriers to employment for persons with disabilities: the potential loss of health insurance once employment is obtained. By reason of their status as SSI or SSDI recipients, TWWIIA participants are eligible for (and most do receive) health insurance coverage under the Medicaid or Medicare programs. Owing to the links between eligibility for cash benefits under these programs and entitlement to this health insurance coverage, many people with disabilities who lose cash benefits as a result of returning to work also soon find themselves deprived of their health insurance as a result. Even when work-returnees can obtain insurance in the private sector, through their employers or through inclusion on a spouse's policy, the extent of such coverage is often insufficient to meet their ongoing or specialized medical needs.

To deal with the work disincentives created by the employment–health insurance link, TWWIIA created a number of means by which individuals with disabilities could retain their federally funded health insurance for substantial periods of time after ceasing to qualify for cash benefits because of income from work. For persons entering employment from the SSDI program, Medicare benefits can now be retained for nearly nine years. For those entering employment after receiving SSI payments, the situation can be more complex, with continued eligibility for Medicaid benefits depending on states' exercise of the discretion TWWIIA grants them to raise the Medicaid income eligibility thresholds.

At a time when many states are financially hard-pressed, their willingness to broaden Medicaid coverage in this way, as well as their ability to provide the applicable state matching funds, may

be open to question. Even states that have implemented the Medicaid buy-in program pursuant to the use of Medicaid infrastructure grants under TWWIIA[88] may find it increasingly difficult to maintain the improvements they have adopted or are contemplating. Accordingly, *NCD recommends that the Administration develop and Congress enact legislation to increase the federal share of Medicaid funds for those states that implement TWWIIA-based reforms in their Medicaid programs and that achieve predetermined levels of return to work and job retention among their SSDI- and SSI-recipient citizens taking part in the program.*

b. EMPLOYMENT NETWORKS

The Employment Networks created under TWWIIA receive payment for their services in a unique way. Instead of receiving per capita, fee-for-service, fixed-periodic-fee, formula-funding, or other traditional types of funding, TWWIIA Employment Networks are reimbursed under a "milestones" system, with maximum payment being available if program participants obtain employment within, and retain employment for, specified periods of time.

If TWWIIA is successful, the service-provider funding mechanism it uses may well become a model for other government-supported employment services, within and beyond the disability sector. Milestone-based and other performance- and outcome-based funding strategies are likely to become increasingly popular in a number of service sectors outside of employment. Use of such a mechanism under TWWIIA reflects the determination by Congress that such traditional funding mechanisms as flat per capita reimbursement or all-or-nothing reimbursement based on "successful outcomes" are inadequate to meet the needs of a hard-to-place job-seeking population or are inadequate to sufficiently motivate the employment services providers who work with the SSI/SSDI population.

As intriguing as this new funding model is, it also poses real risks. What economic incentive do Employment Networks have to work with persons who have the most significant disabilities and with people who need costly AT if the networks' potential reimbursement cannot be increased

sufficiently to defray their added costs and to yield an acceptable rate of return? The Work Incentives Advisory Panel, authorized by TWWIIA and operated by the SSA, is monitoring a variety of issues bearing on the efficacy of the TWWIIA program model. Its Design Evaluation Subcommittee is scheduled to issue a report on adequacy of incentives early in 2002. If this report gives any indication of "creaming" on the part of Employment Networks (that is, of their targeting their recruiting efforts or selection criteria to people with relatively less significant disabilities or with small or nonexistent specialized service needs), the SSA and the Administration should be prepared to move quickly to implement or to recommend to Congress such reforms as are necessary to remedy this situation.

c. TECHNICAL ASSISTANCE AND ADVOCACY

In addition to the state Medicaid infrastructure grants noted above, TWWIIA contains authorization and funding for a number of technical assistance, planning, and related initiatives. One of the potentially most important of these is the benefits planning, assistance, and outreach program (BPAO). The BPAO offers grants for legal assistance, sometimes including state-based protection and advocacy (P&A) systems, to provide benefits counseling, information, and other related forms of assistance (excluding litigation) to TWWIIA participants. Because of the inordinate complexity of the work anti-incentive provisions in the law, BPAO should prove a valuable resource for individuals seeking services and a significant asset to program management and oversight.

TWWIIA is hardly unique, even among employment programs, in presenting legal and procedural complexities to individuals with disabilities seeking to access and benefit from its services. In many employment services, people with disabilities continue to face major barriers: disproportionate investment of program resources in eligibility determinations; evaluations that use inadequate criteria, procedures, or technology; inaccessibility; and reasonable accommodations and exclusionary employer screening practices, just to name a few of the most pervasive. The kinds of information, advice, support, and focused expertise about employment-

related issues that the P&As and other technical assistance providers are likely to develop and disseminate under the TWWIIA program could prove valuable in other settings as well.

Accordingly, *NCD recommends that in the reauthorization of the Rehabilitation Act, the Administration and Congress give consideration to broadening the scope of resources in the employment support area.* Congress should establish a pilot program offering a limited number of competitive grants to P&As or other nonprofit organizations to operate BPAO-type programs that deal with the broad range of employment issues, resources, and rights, with the resources and services of these programs being available to all jobseekers or jobholders with disabilities and applicable to all employment programs.

d. OTHER OVERSIGHT PRIORITIES

For TWWIIA to be fully effective in returning SSDI and SSI recipients to the workforce, a significant number of institutions and entities, some old and some newly created by the statute, will have to work effectively and cooperatively. NCD is confident that the SSA, aided by the advisory panel noted above, will monitor and evaluate all the component parts of the system, ranging from the ability of its own staff to provide clear and adequate information about the new rules to the role of state VR agencies in working with, or in some cases in serving as, Employment Networks. Where any serious problems are found, NCD is hopeful that the SSA will move promptly to correct them or even to seek congressional action to correct them without waiting for the completion of the full five-year reporting period specified in the law.

One area of concern that should be addressed on an ongoing basis relates to the focus of the TWWIIA effort. The new program is organized around the creation of resources at the jobseeking and employment-reentry points. But as the SSA's own statistics indicate, among those few SSDI or SSI recipients who do return to work, job tenure remains a problem, with a sizable number returning to the benefit rolls within a few years. The program does not yet appear to address the ongoing need for follow-up, job retention, and career advancement services

(including in the area of new technology) that many workers with disabilities need. Ultimately, these issues will need to be addressed, and, ironically, the more successful TWWIIA is in returning people to the workforce, the greater and the larger will that need be.

4. FEDERAL HIRING INITIATIVES

a. PERSONS WITH PSYCHIATRIC DISABILITIES

In its 1999-2000 annual report, NCD reported on two Federal Government initiatives designed to broaden employment opportunities available to people with psychiatric disabilities. On June 4, 1999, an Executive Order was issued requiring that individuals with psychiatric disabilities be given the same federal hiring opportunities as people with significant physical disabilities or people with mental retardation. Subsequently, on March 17, 2000, the OPM issued proposed regulations to create a new governmentwide excepted appointing authority for individuals with psychiatric disabilities. This authority broadened the category of people who can noncompetitively acquire otherwise competitive civil service status after two years of successful service, thus providing individuals with psychiatric disabilities the same hiring opportunities already offered to individuals with mental retardation or significant physical disabilities.

Most recently, as discussed in the December 2001 HHS *Olmstead* report, the OPM announced measures designed to further increase employment opportunities in the Federal Government for people with disabilities and to create more uniformity in the provisions applicable to persons with psychiatric and physical disabilities.

NCD commends the OPM for its efforts and believes it would be useful for the OPM to report to Congress and the public on the results of its efforts to date, on the recruitment or other outreach measures it has adopted, and on the tenure and upward mobility of persons who have entered federal employment as a result of these programs. *NCD particularly recommends that OPM indicate the applicability of these competitive-appointment exceptions and exemptions to the*

promotion and advancement opportunities available to persons with disabilities in each of the three categories—significant physical disability, mental retardation, and psychiatric disability—covered by these programs.

b. REASONABLE ACCOMMODATIONS

NCD also commends the OPM for its announcement on December 11, 2001, of rules requiring all federal agency job vacancy notices to include language apprising applicants of the availability of reasonable accommodations.[89] In light of these notice requirements, NCD believes that a full assessment of the reasonable accommodations procedures and practices used by the Federal Government to implement hiring and promotion policy could prove quite valuable. Accordingly, we urge OPM, acting in concert with OMB or such other entities as may be appropriate, to study and report on the level of awareness among federal personnel officers regarding the meaning and availability of reasonable accommodations; the budgetary strategies available for providing reasonable accommodations; the time frames and authorization processes associated with the selection and implementation of reasonable accommodations; and the methods used by agencies to obtain and evaluate employee input into the choice of accommodations.

5. DEMONSTRATION PROJECTS

In last year's report, NCD reported on a number of interagency and public-private initiatives and demonstration projects designed to increase employment opportunities for people with disabilities and to break down barriers to the employment of people with disabilities. Several of these initiatives also were intended to increase the ability of state-based and other mainstream employment services to incorporate people with disabilities into their activities and programs.

Agencies included in these demonstrations were the SSA, the HHS, the DOL, and the ED. The programs included award by the ED of six systems-change grants to establish models of improved cooperation and coordination among state vocational rehabilitation programs, public

employment training programs, and other related programs. In addition, the SSA was working under cooperative agreements with 12 states to develop innovative projects to help adults with disabilities reenter the workforce. Moreover, prior to its absorption into the new ODEP, the President's Committee on Employment of People with Disabilities worked to coordinate a commitment by the U.S. Chamber of Commerce, the Society for Human Resource Management, and dozens of private sector companies to support several initiatives to advance the employment of people with disabilities.

Based on the New Freedom Initiative, as reflected in the *Olmstead* report, Administration and the nation clearly stand on the threshold of an exciting array of potentially innovative and productive employment initiatives involving federal agencies and a significant number of public and private sector partners. In the interests of knowing what works and because of the importance of continuity, *NCD recommends that all the agencies spearheading last year's initiatives provide updates on whether these programs continue in operation and on what results or methodologies they have yielded.*

6. ONE-STOP CAREER CENTERS

In 1998, Congress adopted the Workforce Investment Act (WIA),[90] which, among other things, sought to simplify the bewildering web of federal labor market and employment programs. From the standpoint of increased efficiency and greater customer satisfaction, one of the WIA's key ways of doing this was the establishment of one-stop centers where jobseekers could access and obtain all relevant public services and information, could handle all key documentation and access all necessary databases, and could make all necessary contacts from one central location in their area.

Although the parallel VR system for individuals with disabilities was not abolished or merged into the one-stops (in fact, the Rehabilitation Act Amendments of 1998 constitute Title IV of the Workforce Investment Act), the one-stops were expected to be available and accessible to all

persons, including persons with disabilities, and they and the state VR systems would establish cooperative working relationships to pool their strengths and resources on behalf of jobseekers with disabilities. Serious unanswered questions persist about whether and to what extent such pooling of resources or combining of strengths has in fact taken place

For example, informal reports from people around the country paint a troubling picture of one-stop center inaccessibility. Among other problems, electronic and information technology (E&IT) used for job searches and other activities is frequently not accessible to persons with disabilities. As discouraging, one-stop center officials are reported in several instances to have asserted that the funds for making their E&IT accessible should not have to come from their regular funding but from extra funds, specifically appropriated or allocated for accessibility purposes.

No major litigation regarding the accessibility of one-stop centers, invoking either Section 504 or Section 508 of the Rehabilitation Act, is yet known to have commenced. But rather than await such litigation, *NCD recommends that the DOL move swiftly and decisively to clarify the applicability of federal civil rights laws, including Sections 504 and 508, to the facilities and technology of the one-stop centers and to ensure that accessibility requirements are implemented with as much energy as any other of the legal standards that bear on the operation of these centers.* In this connection, the DOL should also review the technical assistance currently available to one-stops for purposes of ensuring that the centers understand their responsibilities under the law and making certain that the centers will not inadvertently overestimate the costs or difficulty of accessibility because of lack of adequate information regarding its principles.

7. LICENSING AND FUNDING

Elsewhere in this report, we argue for vigorous enforcement of federal civil rights laws through the funding and regulatory roles played by the Federal Government. Where public funds help to defray the cost of an activity, the recipients of such funds (whether or not the funds are

denominated as "federal financial assistance") properly should be expected to abide by civil rights laws, just as they are expected to adhere to a host of other important laws. Similarly, NCD believes that in certain cases in which the federal role involves the regulation or licensing of activities, it is likewise reasonable to expect compliance with all laws by those so regulated and protected by the government, by its licensing and regulatory authority, against competition.

A number of legal complexities surround the broad-based application of these principles. Recent court decisions have, for example, drawn sharp distinctions between the authority of the FCC to enforce civil rights and its jurisdiction to mandate any form of "affirmative action."[91] Whereas a fine line may in some instances exist between protecting civil rights and requiring entities to engage in affirmative activities that go beyond the traditional notions of the meaning of nondiscrimination, NCD strongly believes that accessibility of E&IT paid for with federal funds, no less than accessibility of buildings and facilities constructed with federal support, falls clearly on the civil rights side of that line.

NCD also recognizes that the authority of the government, even when paying the freight, may be far less in its dealings with private sector partners than with units of government. Elsewhere in this report, NCD recommends that the DOJ comprehensively study the question of whether the Federal Government is making optimal or consistent use of its funding relationships to maximize its leverage on behalf of accessibility. At least in those circumstances in which the nature of the relationship meets the standards for federal financial assistance established under Section 504 or the purpose of the relationship includes information dissemination activities that bring the E&IT used by the private entity within the scope of Section 508, suggesting that adherence to principles of accessibility can fairly be demanded and expected is surely not unreasonable.

But even apart from such a DOJ study, the implications of accessibility for employment and for access to employment opportunities are especially pressing and immediate. Thus, pending the DOJ'S action on this recommendation, *NCD recommends that each federal agency involved in job-creation efforts or in the funding of programs that create or support jobs involving E&IT*

independently evaluate the extent of its responsibility and the scope of its authority for ensuring the accessibility of these programs, jobs, and information resources to all the taxpayers who help fund them.

8. TAX INCENTIVES

The past year has demonstrated the Administration's strong belief in the role of tax policy as an engine for stimulating economic growth and for encouraging employment. Indeed, recognizing the enormous power of tax policy, the Administration's Fall 2001 economic stimulus proposals for reviving the economy placed heavy emphasis on tax relief as the lever for unleashing and renewing the job-creation capabilities of American industry and commerce. In light of this precedent, it is appropriate to ask what tax incentives could hold value for enhancing the employment of persons with disabilities.

Although the Administration and Congress have on balance favored tax rate reductions as the approach of choice to tax policy, all of the modifications to the Internal Revenue Code adopted over the past several years have included targeted provisions aimed at addressing matters that are not responsive to changes in tax rates alone. The timeliness of tax reforms aimed at incentivizing the employment of persons with disabilities is heightened by the fact that, pursuant to Section 303 of TWWIIA, the Government Accounting Office (GAO) is currently launching a study of existing disability-employment incentives currently in the law. *NCD recommends that the GAO analyze these provisions—including the disabled access credit,*[92] *the architectural and transportation barriers removal deduction,*[93] *and the disability-related portions of the work opportunity credit*[94]*—with a view to measuring their economic and social impact along with their cost to the Treasury and with a view to eliminating historically explicable but no longer relevant limitations on their availability.* Examples of such outmoded provisions include limitation of the work opportunity credit to those persons with disabilities who have received SSI (not SSDI) in the past two months or who have completed a program of vocational rehabilitation and been certified by the state VR agency (not by a TWWIIA Employment Network or by a one-

stop center). Another example is the applicability of the barrier-removal deduction only to a restricted category of physical barriers but not to communications or information-access barriers.

In maintaining such limitations on the scope of these provisions and on their use by business, the law does not reflect any policy. Rather, such restrictions as these simply reflect the fact that these provisions were enacted at a time when the concept of E&IT accessibility or communication barriers to access had not yet entered our lexicon or our consciousness.

Whereas the legislation authorizing the study does not explicitly mandate their inclusion, NCD hopes that the GAO will find it possible and within the scope of its assignment to include employee- as well as employer-based incentives in its study, particularly at a time when bottom-line pressures may force employers to cut back on fringe benefits and may lead some employers to be more resistant to the provision of even tax-deductible reasonable accommodations than might formerly have been the case. Tax incentives aimed directly at employees (rather than at their employers), such as the impairment-related work expenses deduction,[95] may make the difference between ability and inability to work in an increasing number of cases.

Chapter 8
Welfare Reform

In 1996, "welfare as we know it," to use former President Clinton's famous campaign phrase, did indeed come to an end with the passage of the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA).[96] Now, as PRWORA faces reauthorization in the second session of the 107th Congress, welfare as we have come to know it is once again under the microscope of congressional and public scrutiny.

As the law comes up for review and reauthorization, with many people having exhausted their five years of eligibility for welfare assistance, Congress and the Administration come to their task in a changing economic climate and with many new issues and questions to be confronted. Some of those questions, many of which have not been featured in discussions of welfare reform up to now, involve the interplay between welfare and disability. Specifically, these questions relate to the connection between so-called welfare and specialized disability-oriented income maintenance programs and to the ability of, and the mechanism for, state welfare reform systems to provide the technical assistance and support services that recipients with disabilities may need to enter and thereafter retain and advance in employment.

One of the most intriguing features of PRWORA is the flexibility it accords to states in the ways they implement welfare reform and in the system of reimbursement established to encourage and reward success. Typical of this approach are provisions allowing states to retain unspent funds if they achieve specified welfare caseload, work, and other goals and provisions linking the availability of recipient time-limit extensions and the waiver of other provisions to states' success in meeting a number of program targets and outcome goals.

Within this framework, one key question to ask relates to the different ways states may have attempted to link their welfare reform systems and their various disability programs. In its reauthorization deliberations, Congress should seek information on the extent to which job

training, counseling, transportation services, day care, and other components of welfare reform programs have included or used screening for disabilities that might complicate program participation or jeopardize success; the degree to which states have helped or have required subcontractors to provide reasonable accommodations (ranging from accessible vehicles to specialized child care) to facilitate the participation of welfare recipients with disabilities or welfare recipients who are caregivers for persons with disabilities in return-to-work programs; and the efforts that have been made to enlist the services and resources of the VR system on behalf of welfare recipients who by reason of disability may also be eligible for these services.

NCD hopes that in its consideration of reauthorization, Congress will seek and obtain testimony and information on these issues. Only in that way can the impact of welfare reform on recipients with disabilities (particularly recipients with hidden disabilities) or on families having members with significant disabilities be fully assessed, and only with the elucidation of such information can consensus be reached over the priorities for any new legislation in this area.

The involvement of the VR system or other disability-oriented service systems in the welfare reform effort might create new coordination and allocation-of-responsibility issues; however, it seems likely that, properly brought to bear, the resources and expertise of these service systems could contribute to the assessment of disabilities, including hidden disabilities, in a number of instances and could increase the likelihood of success in the return-to-work efforts of individuals with disabilities. Pending elaboration of what has been tried and accomplished in this area, we do not offer any specific recommendations at this time but do expect to be able to do so as the public discussion proceeds.

Attention to the effects of welfare reform has thus far tended to concentrate on the reductions in caseloads and in the welfare rolls that have occurred since passage of the law. But with the passage of time, information on other outcomes, including the job tenure of former recipients, will become increasingly necessary. For former recipients with disabilities, such information may be particularly important, bearing as it does on the follow-on and support services, from

wherever they ultimately come, that these former welfare recipients will need in order to become long-term productive members of the economic mainstream.

In connection with the flexibility PRWORA accords to the states, one of the most interesting features of the law's structure is its approach to waivers. In a number of settings, the extent to which extensions are available for the five-year lifetime limits on receipt of Temporary Assistance to Needy Families (TANF) or the availability of waivers of other requirements under the law hinge on a state's success in meeting or exceeding a variety of program targets. Congress may wish to consider adding provisions that reward states, either with administrative flexibility or with extra funds, based on the extent of their efforts and success in developing appropriate and reciprocal links between their welfare reform and disability services systems. Such links cannot but prove beneficial to all parties by increasing the resources available for persons with disabilities or persons with major caregiving responsibilities to enter, reenter, and remain in the workforce and by increasing the likelihood that work with such persons will have positive, long-term results. When it comes to working with recipients with disabilities, state welfare reform systems should not have to reinvent the wheel. Measures should be taken to ensure that the resources and expertise of the state VR and other disability services programs are available to contribute to the successful outcomes that all seek.

Chapter 9
Housing

Shortages of affordable housing are widely recognized to represent one of the major problems facing persons of moderate and low incomes in our country today. For persons with disabilities, this problem may be even more acute, because affordability for them is conditioned by inaccessibility, availability, and discrimination. Put another way, the supply of otherwise affordable housing that many Americans with disabilities can purchase, rent, or even visit is limited by the fact that much of our housing stock is not accessible and, even if it is accessible, discrimination may stand in the way of its availability and occupancy.

Housing plays a profound role in all aspects of people's lives. The time and distance involved in getting to and from work (which are both reported to have increased during the 1990s); the amount of discretionary income remaining for education, health care, or even food and clothing after housing costs have been met; the level of physical safety and personal security people feel in their environments as a result of the kinds of neighborhoods and communities in which they live; the proximity to toxics or other environmental hazards; and the quality of education readily available to one's children all, along with other elements of life, are directly and powerfully related to the options that people have in housing.

Any systematic effort to increase the stock of accessible, affordable, and available housing for persons with disabilities must take account of the overall housing situation faced by the United States. That is a situation that contains some remarkable and some disheartening components. For Americans as a whole, home ownership stands at or near historic highs. An October 2000 Department of Housing and Urban Development (HUD) press release indicated that more than two-thirds of Americans lived in homes that they or their families owned. Levels of home ownership, traditionally considered a bellwether of social progress and stability and the hallmark of the American dream, have also risen impressively among minority groups. But among the

minority group of Americans with disabilities, rates remain shockingly low, languishing in the single digits, according to another recent study.[97]

The significance of affordable, available, and accessible housing has received some recognition from the Administration. Pursuant to Executive Order 12892, the President's Fair Housing Council has been created, and its establishment served as the occasion for statements of commitment to fair housing enforcement on the part of leading officials, including the secretary of HUD and the attorney general of the United States. More recently, the importance of housing issues has again been acknowledged by the Administration in its preliminary *Olmstead* implementation report issued in December 2001.[98] HUD was a participant in the agency self-evaluation process leading to that report. HUD'S involvement and the considerable attention the report paid to plans and recommendations for upgraded enforcement and other program enhancements in the housing and fair housing areas reflect the awareness that our ability to meet the aspirations of people with disabilities and older persons for deinstitutionalization or to remain in their own homes depends on the availability of adequate housing for them. Unless communities across the country can meet this need for housing, the aspiration for and the momentum toward community living surely will be blunted to a considerable degree.

NCD has long maintained a profound concern over housing issues and has addressed its attention to the matter in a number of reports and studies. In the report of its 1996 disability summit, *Achieving Independence*, NCD made a number of recommendations regarding housing and the Federal Government's enforcement role. Our 1999-2000 annual report reviewed a number of policy activities undertaken by the Federal Government in 2000 relating and responding to many of NCD'S recommendations from the *Achieving Independence* report. Most recently, NCD released its major report *Reconstructing Fair Housing*[99] on November 6, 2001. This report catalogued serious, pervasive, and persistent weaknesses and failures in the Federal Government's enforcement of nondiscrimination laws in the area of fair housing. These findings and recommendations will be summarized in this chapter.

Before proceeding to a discussion of the specific issues raised by the *Reconstructing Fair Housing* report, it is important to note that the report covers the period ending September 30, 2000. The patterns and practices the report finds are long-standing and implicate successive administrations of all parties and persuasions. The existing and deep-seated problems *Reconstructing Fair Housing* discloses will require sustained, concerted, and high-level attention if this tragic legacy of missed opportunities is truly to be overcome.

1. FAIR HOUSING AND EQUAL OPPORTUNITY

NCD commends HUD for its receptivity to our report and for its willingness to disseminate the report to its regional offices and enforcement staff. Considering the highly critical nature of many of the report's findings, this openness is particularly welcome. The task now is to bring about the improvement for which the report calls.

a. ORGANIZATION OF THE ENFORCEMENT EFFORT

HUD is responsible for enforcing three major civil rights laws: the Fair Housing Act of 1968[100] (which applies to the sale and rental of all public and most private housing), the Fair Housing Amendments Act of 1988[101] (which adds "handicap" and familial status—the presence of children in the household—to the list of those protected against housing discrimination), and Section 504 of the Rehabilitation Act (which bars discrimination, including discrimination in housing, by recipients of federal financial assistance). Additionally, HUD has a role through Title II (public housing and certification of state building codes) and Title III (private sector) in enforcing the ADA.

Primary responsibility for enforcement is vested in HUD's Office of Fair Housing and Equal Opportunity (FHEO), but various cycles of reorganization, decentralization, and recentralization have occurred over the years. HUD also has an Office of Disability Policy, but its role in the enforcement process and its relationship to other units of the department are not entirely clear.

Enforcement resources budgeted for and committed to FHEO have declined steadily since 1989 and stand at approximately half the levels of that year.

b. COMPLAINT HANDLING AND CASE PROCESSING

Because the Fair Housing Amendments Act (FHAA) and Section 504 differ in the procedures, jurisdictions, statutory time frames, and other variables applicable to their enforcement, some variation in complaint handling and case processing must be anticipated between the two laws. Recognizing this threshold problem, HUD has undertaken to prepare new informational materials for the public and for those involved in the housing industry aimed at clarifying the department's jurisdiction and enforcement role. Although such information will be of value, any resultant increase in the number and quality of complaints filed may lead only to further frustration, alienation, and public distrust of the fair housing enforcement system unless accompanied by thoroughgoing reforms in the ways HUD processes, tracks, resolves, and, where appropriate, refers complaints.

The levels of this lack of confidence that *Reconstructing Fair Housing* revealed are not difficult to understand in light of the underlying data. The average age-of-case at disposition had mushroomed to 497 days, nearly five times the 100-day benchmark period fixed by Congress. Even when cases were concluded by HUD, few ended in findings of "cause" and fewer still in any adjudication or enforcement action being taken.

By 1999, after having become the fastest growing complaint category, disability discrimination complaints, representing 42 percent of all complaints received, came to constitute the most frequent type of complaint filed with the department. Yet, HUD lacked the most basic mechanisms for disseminating legal or other guidance to its enforcement personnel, had no system for informing staff of best practices in case investigation, and had even failed to apply some of the investigative and management tools developed in the FHAA area to its work under Section 504. Finally, state and local fair housing enforcement agencies, supported under HUD's

Fair Housing Assistance Program (FHAP), actually resolved and disposed of cases more quickly than the department did.

c. FUNDING

In connection with efforts to upgrade HUD's fair housing enforcement, the department requested an increase in funding for fair housing and equal opportunity enforcement in its FY 2002 budget request. Congress did not include these additional funds in the HUD budget appropriation. Observers report that, pending improvements in other long-standing management deficiencies within the department, Congress is disinclined to grant such increases.

Whereas NCD understands that the means available for Congress to express its disapproval of any executive branch agency are relatively few, with budgets being among the chief means for enforcing its wishes, we regret that people with disabilities and other groups who look to fair housing enforcement as a tool for protecting their rights should be held hostage to problems that they did not create and certainly cannot solve. Especially in light of the data collected in *Reconstructing Fair Housing* concerning declines in funding for enforcement during the 1990s, NCD hopes that the Administration will continue to seek funding for meaningful increases in fair housing enforcement, either through a supplemental budget request or through the achievement of savings in other HUD programs that could free up funds for reallocation to the department's equal opportunity work.

Another area in which funding shortages may have played a critical role in program underperformance is that of technical assistance. HUD's fair housing initiatives program (FHIP), for example, is designed to assist state, local, and private fair housing agencies as well as advocates. But *Reconstructing Fair Housing* finds that this program suffers from many problems, including underfunding, lack of monitoring, and poor performance. Although the potential value of this program for the expansion of fair housing resources in the community or for the education of the public and the building industry about fair housing and accessibility

cannot be known with certainty, our growing recognition of the limits on the power and the role of the Federal Government require that such efforts as FHIP be given every chance to succeed. Accordingly, *NCD recommends that any review of the levels and allocation of HUD funding take the needs and importance of such programs as FHIP and the related FHAP (Fair Housing Assistance Program) fully into account.*

d. ENFORCEMENT

Whether as a response to NCD'S *Reconstructing Fair Housing* report or independently of it, the *Olmstead* implementation report devotes considerable attention to plans by HUD and the Department of Justice (DOJ) to step up enforcement efforts, including coordination in the referral of cases by HUD to the DOJ for prosecution and litigation where appropriate. To that end, the DOJ indicates its intent to meet with HUD on a quarterly basis, and the two agencies express an intent to monitor and use guidelines for selecting cases that are appropriate for such referrals.

But whereas structuring of the referral relationship in this fashion (however it may be that DOJ postulates no comparably specific schedule of contacts for fostering its referral relationships with other agencies) clearly represents an important step forward in fair housing enforcement, NCD notes a number of anomalies in the Department of Health and Human Services (HHS) *Olmstead* report's description of these proposed new efforts. Most notable in this regard is the specification of entities to be targeted for enforcement. In several iterations of its plans in this regard, HUD clearly places a focus on those who design, fund, and build housing, speaking of architects, engineers, and similar categories as its objects of proposed enforcement. These groups fall mostly on what we may call the production end of housing. When it comes to what we may call the retail end of the process, HUD is not specific or expansive about the targets of its enforcement. With the exception of public housing authorities, the HUD plans described in the *Olmstead* report appear to make no reference to the variety of individuals and institutions involved in the sale, rental, or management of private housing. To be sure, HUD does indicate its

intentions to revive its fair housing testing program, which could address these sectors of the housing industry.

By contrast, the DOJ, for its part, does make reference to people who manage rental properties as an appropriate enforcement category, but even the DOJ, insofar as the *Olmstead* report summarizes its intentions, appears to make no reference to real estate brokers, mortgage lenders, or others involved in the buying and selling of homes. If, as we hope, this omission is merely a function of editing for space, it is of no significance. But if it reflects the enforcement priorities of the DOJ in this area, then it is especially regrettable given the concerns about low home ownership levels among people with disabilities noted above.

e. AGED CASES

Because of chronic delays in case processing noted above, HUD has a large backlog of aging fair housing cases. How to deal with that backlog is a question of great importance. In a recent letter to the HUD secretary, NCD cautioned against solving the problem by simply dismissing or otherwise purging the oldest cases.[102] NCD points out that whereas justice delayed is justice denied, dismissal of cases solely on the basis of their age is arbitrary and only adds further injustice to that which is inherent in delay.

f. ACCESSIBILITY SURVEY

The rules governing the construction and renovation of housing are part of the fabric of fair housing. Yet, because of differences in the requirements among civil rights statutes, and perhaps owing in part to the erratic nature of HUD's enforcement from time to time and region to region, HUD has undertaken to help remedy this problem through the development and dissemination of informational resources, as noted above. In addition, to give the real estate building and management communities the clearest possible guidance on what the law expects of them when they build or renovate housing and to give people with disabilities or other interested persons a

chance to comment on the current codes implementing the ADA and related accessibility laws, HUD has commissioned a survey on accessibility needs.[103] In the conduct of this survey, as in all its other deliberations concerning the definition of compliance with the ADA in housing, concerning the standards by which compliance with Section 504 will be measured, concerning any further attempts at model code creation in which the department may become involved, and concerning the certifiability of state building codes as compliant with ADA standards, HUD should remember that we confront new accessibility issues today that did not exist when the ADA and its implementing regulations were written.

One of the most striking examples of such emerging issues involves the building or renovation of homes with central heating and air-conditioning or with built-in kitchen appliances that are inaccessible to persons who are blind or have other disabilities of reading or even for people who lack the motor function to align the various pointers and dials or to respond quickly enough to moving digital displays. The time was when people who could not see the dials and settings on their thermostats or kitchen appliances could affix braille or large-print labels to the controls. Many public utilities and some appliance manufacturers offer templates for these purposes. But the digital displays and touch-panel controls that are used in modern design do not lend themselves to being made accessible by any of these means.

If the thermostat or other furnace controls in a new home were located so high on a wall as to be unreachable by a person using a wheelchair, we would have no problem in deeming those controls, and therefore that home, inaccessible. Apart from any questions of comfort or convenience, such a design would pose real risk to health and safety, including even the risk of asphyxia or, in some climates, of harm through cold or heat. Yet, when, because of the failure to implement readily achievable design features, people who are blind are subjected to the same risks, the law thus far appears to take no notice and to manifest little concern.

Inexpensive technology exists for providing audio or tactile output for thermostats, timers, and oven and refrigerator controls, but it is not technology that can be retrofitted. It must be

incorporated into the original design. No survey of accessibility concerns, and certainly no revision or updating of ADA design requirements, can be regarded as adequate or complete if it does not take account of this growing accessibility barrier.

HUD should immediately begin inquiries necessary to issue regulations that will incorporate accessibility of air control, environmental control, and built-in appliances into the cannon of legally required measures. HUD should evaluate its legal authority to do this under all the civil rights statutes it administers. If it determines itself to lack authority to require this form of accessibility under any of the applicable laws, the Administration should consult with the disability community and the Access Board to develop a legislative strategy to allow such protections to be added. If HUD finds it has the authority to act under the ADA, it should promptly undertake the inquiries and information-gathering necessary to do so, without waiting for legislation to give it parallel authority under the other fair housing statutes it enforces.

Given the small cost and little difficulty of the measures that developers, architects, and builders need to take in order to prevent these forms of inaccessibility from occurring, no justification should exist for failing to take these simple measures that would enhance the health, safety, and comfort of our citizens with visual impairments, including many elderly persons whose prospects for age-associated vision loss and mobility impairment are high.

g. VISITABILITY

In 2000, HUD proposed to increase the number of new-construction housing units available to persons with disabilities by awarding bonus points for developers who build structures that include "visitability" by people with disabilities. Visitability involves the incorporation of a number of accessibility features that make it possible for people with disabilities to enter, function reasonably within, and remain in dwelling units, whether or not those units have been specifically designed or designated for occupancy by people with disabilities.

During 2001, Vermont became the first state to add visitability to its state building code. Relating to such matters as the availability of at least one step-free entrance, the width of doorways, the design of a bathroom, and some other matters, visitability is important not only for the possibilities of social and professional interaction it creates but also for the elimination of artificial and destructive distinctions between housing built for people with disabilities and housing built for everybody else. *NCD strongly supports state and federal visitability initiatives and recommends that HUD take the steps necessary to make visitability an element of federal policy with respect to all new and renovated housing in our nation.*

2. HOUSING SUPPLY

Although vigorous enforcement of antidiscrimination laws in the short run and comparably vigorous implementation of accessible design requirements in the long run can contribute significantly to the supply of available and affordable housing, these laws cannot by themselves create the supply of housing that we need. Other measures designed to expand the accessible housing stock and aimed at making such housing affordable are necessary as well. In this regard, several measures commend themselves to the attention of HUD, Congress, and the general public.

a. VOUCHERS

Changes in law that increased investment in "elderly only" buildings ironically resulted in a decline of available housing for people with disabilities. To help rebalance the situation, funding for Section 8 rental housing vouchers was increased in 2001, but increases in rental housing prices caused by the overall supply-and-demand equation in our nation have combined with a shortage of vouchers to pose growing difficulties for those who need this sort of assistance. Realizing that vouchers represent at best only a partial and temporary solution to the problem, *NCD nevertheless recommends that their use and availability be maximized and rationalized during the time required for other, longer-term measures to begin taking effect.*

b. INTERIM STRATEGIES

Whereas increases in the number and the value of Section 8 vouchers, together with some changes in the rules to which landlords who participate in the Section 8 program must subscribe, would help to ease the shortage, the most meaningful long-term answers continue to lie in increasing the accessible housing stock of our nation and of course the resources of people with disabilities through work and other measures of integration into the mainstream economy. The tax code offers several strategies for increasing the supply (and hence the affordability) of accessible housing. Three measures can be recommended for further study here. The first is the enactment of an accessible housing credit, modeled on the low-income housing credit. The second is to expand the architectural barrier removal deduction so that it is available not only to businesses but also to the owners of single- or multiple-dwelling residential properties for the removal of architectural barriers, meaning the addition or incorporation of accessibility into existing buildings. The third tax strategy, which would need to be implemented prospectively, ideally going into effect three to five years after enactment, is restriction of the tax advantages, including the deductibility of home mortgage interest and real estate taxes, in connection with newly built or substantially renovated residential property that does not meet accessibility standards prescribed by law.

Beyond such tax law refinements as these, several other strategies also recommend themselves, two of which are noted here. The first begins with the assumption that more people would request or insist on accessibility in their purchase of homes if they knew about the issue and knew what accessibility meant. Both these goals could be hastened by revising the contents of federally required disclosure statements so they would be required to include information on the home's degree of accessibility, according to the applicable legal standards. State home-sales disclosure requirements should likewise be revised to the same effect. Nothing in the disclosure process would require that the home be accessible, but buyers have a right to know whether and to what extent it is, and representations concerning accessibility, once made, should be regarded as material to the transaction for all subsequent legal purposes.

The second strategy in this connection is the Community Reinvestment Act (CRA). The CRA should be revived and amended to clarify that investments in community-based accessible housing represent the type of activity the law is intended to encourage.

3. HOME OWNERSHIP

Owning a home of one's own is part of the American dream, no less so for people with disabilities than for anyone else. Yet, despite the gains made by Americans with disabilities over the past generation in many areas of life, home ownership continues to be massively out of reach. As mentioned, statistics released by HUD in October 2000 indicated historically high home ownership rates among all categories of Americans. Even families with incomes below the median registered considerable gains in this area. For members of minority groups, the home ownership rate stood at just higher than 48 percent. Considering this level still to be too low, HUD indicated that bringing the home ownership for Americans of minority backgrounds above 50 percent was one of its goals.

So Americans from all groups were attaining this embodiment of the American dream in rising and record numbers, except, that is, Americans with disabilities. For people with disabilities, the rate of home ownership was dismally low. HUD has not, so far as is known, expressed either outrage over this figure or any intention to prioritize the effort to do something about it.

Some may say that because of the strong association between disability and low income, low rates of home ownership among people with disabilities are in no way surprising. They would ask, in effect, "What do you expect?" The problem is not that simple, as evidenced by the reported increases in home ownership among persons of low and moderate income generally, and among the often economically disadvantaged group comprising households headed by women.

In addition to the inherent barrier created by low income, restrictive Supplemental Security Income (SSI) regulations and provisions governing other programs prohibit recipients of benefits

under these programs from accumulating enough savings to afford the down payment, closing costs, or reasonable maintenance, taxes, and repairs associated with home purchase and ownership. Medicaid ordinarily allows people to keep their homes, which is particularly valuable for elderly persons, but its income and resource eligibility rules also work to prevent people from buying homes in the first place.

Precedents for how to overcome this barrier can be found in SSI's income and resources disregards for funds used in Social Security plans to achieve self-support and in such experimental vehicles as medical savings accounts (MSAs). NCD proposes a pilot demonstration to be conducted under the authority of the Social Security Administration (SSA) whereby SSI or Medicaid recipients would be allowed to establish home ownership accounts that could be used to accumulate funds for down payments, closings, and reasonable maintenance and that would not be subject to "countability" for purposes of the income and resource limitations applicable to these and other means-tested programs.

Government loan guarantee programs, including Fair Housing Amendment (FHA)-guaranteed and Department of Veterans Affairs (VA) loans, are one way of reducing these barriers. Existing outreach programs should be examined and new targeting efforts undertaken to provide loan guarantees for minimal down payments to persons with disabilities. Efforts should also be undertaken to ensure that the FHA and VA approval processes are fully accessible to individuals with disabilities. Accordingly, *NCD recommends that the panoply of federal housing loan guarantees be reviewed for accessibility, for barriers, and for models that could allow information and assistance to be targeted more effectively to persons with disabilities.*

During the first session of the 107th Congress, a number of bills were introduced to facilitate home ownership by public safety officers and teachers by reducing down payment requirements, by increasing the availability of federal loan guarantees, and by other means.[104] Congress should direct attention, initially on a pilot/experimental basis, to whether a similar approach on behalf of

gainfully employed individuals with disabilities could increase levels of home ownership among this population.

Another area of possible government action, and one that HUD has indicated it does have under consideration, involves the modification of the rules governing Section 811 Tenant Assistance to allow these resources to be used for home ownership as well as for rental. *NCD recommends that HUD pursue these efforts vigorously, including proposing necessary legislation to Congress if that is required to make program expansion along these lines possible.* But one crucial caveat must be emphasized here. Owing to the extremely limited availability of rental housing voucher and other subsidy funds under current law and budgetary conditions, any such use of Section 811 funds should be undertaken only in the context of assurances that it will not place further burdens on, or create greater competition for, the limited rental housing resources now available. New funds only should be used to support this home ownership initiative.

Chapter 10
Transportation

1. AIR TRAVEL

Nothing has changed more dramatically and irrevocably in the past year than the way we travel by air and the way we experience and think about that travel. Inconveniences and delays that might once have provoked a storm of protest are now tolerated, even welcomed, by passengers, who recognize the imperatives of safety and security. But within the framework of concerns shared by all, many transportation issues unrelated to security continue to exist, including issues relating to the ways air carriers and airport operators treat, accommodate, and provide services to passengers with disabilities.

In March 2000, Congress enacted the Wendell H. Ford Aviation Investment and Reform Act for the 21st Century (AIR-21),[105] which contains important changes to the Federal Aviation Act and to the Air Carrier Access Act (ACAA) of 1986. These amendments strengthened in both laws the mandates of nondiscrimination against air travelers with disabilities.

One provision of the amendments recommended by NCD was for foreign air carriers operating within the U.S. air transportation system to follow the same rules of nondiscrimination as domestic carriers. To implement this provision, AIR-21 called on the secretary of transportation to work with appropriate international organizations to establish higher international air transportation standards for accommodating air travelers with disabilities.

In last year's report, NCD urged the secretary of transportation to exercise leadership in bringing together representatives of key international aviation organizations to reach agreement on international standards of accommodation. During the intervening year, the importance of international cooperation among air carriers and governments has been demonstrated more clearly than ever before. Although NCD recognizes that unprecedented demands on the resources

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of the Department of Transportation (DOT) over the past few months and into the foreseeable future must inevitably limit the attention the DOT can devote to any matters other than security, NCD is mindful of, and highly commends the department for, recent steps (that will be discussed) that show it has not lost sight of, or abandoned concern for, the issues affecting passengers with disabilities.

NCD asks the department to indicate what progress has been made toward implementing the international agreements set forth in AIR-21 and, if the requisite bilateral or multinational agreements have not been negotiated or implemented, to indicate its best sense of what the prospects are for doing so in the next year and what, if any, further resources or legislative support would be of assistance to it in pursuing and completing these policy objectives.

The AIR-21 amendments required the secretary of transportation to investigate each complaint of an ACAA violation and increased the penalty for violation from $1,100 to a maximum of $10,000 for each offense. AIR-21 also required the secretary of transportation to publish disability-related complaint data in a manner comparable to other consumer complaint data compiled by the department, to regularly review all complaints received by air carriers alleging discrimination on the basis of disability, and to report annually to Congress on the results of such review. To support greater compliance, the secretary was instructed by the statute to work with the DOJ, the Architectural and Transportation Barriers Compliance Board (Access Board), and NCD to develop a technical assistance plan and make materials available to individuals and entities with rights and responsibilities under the law.

NCD commends the DOT for the steps it has taken over the past year to fulfill the letter and the spirit of these amendments. In particular, we note the outreach efforts undertaken by the DOT to gather information from travelers with disabilities concerning problems they face. Additionally, inclusion of air travelers with disabilities in the Air Traveler Customer Survey was withdrawn pursuant to an Office of Management and Budget (OMB) directive.

Bearing in mind that the Air Traveler Customer Survey was undertaken as an alternative to further regulation, NCD recognizes that compliance with the recommendations contained in the DOT inspector general's report has been voluntary on the part of the airlines. NCD therefore asks the DOT to what extent domestic (and, if applicable, foreign) carriers have complied with these recommendations, particularly those dealing with the need for timely and appropriate assistance. If compliance (as judged by the ACAA complaints received or through other data sources) is deemed high, the industry is likewise to be complimented. But if the recommendations in such areas as passenger assistance and advisory committees have not been implemented, NCD recommends that the department consider regulatory measures as an adjunct to these voluntary efforts.

NCD also appreciates the DOT's issuance of a number of ACAA fact sheets, including the recent fact sheet reiterating and reinforcing the continued commitment to ACAA and the DOT's recognition that ACAA and heightened security are entirely compatible and can and should coexist.[106]

In spite of DOT's timely fact sheet, anecdotal reports from air travelers with disabilities indicate that additional issuances, embodying more specific examples of how security and civil rights intersect, may be necessary if the air transportation system is to effectively unite ACAA with heightened security principles. Specific problems reported over the past few months include airport personnel regarding suspiciously or even threatening to remove or confiscate assistive devices, such as canes, even though they had been fully inspected and found to harbor no concealed contents; airport personnel refusing to assist passengers with visual or mobility impairments in recovering their belongings once they have come off the conveyor belt after going through screening, and refusing to tell such passengers, when their bags could not be found among those that had come off the belt, that the bag had been taken aside for hand inspection; officials being unaware that escort or assistance personnel are permitted to accompany passengers with disabilities to and from their gates, and airports failing to make clear what the procedures for obtaining such permission are; officials refusing to believe that service animals

are entitled to carriage in the passenger cabin with the passenger; officials refusing to offer various kinds of needed assistance except on arbitrary and humiliating terms (such as refusing to drop off passengers with disabilities at restaurants but insisting that if their gates are not yet open they be taken to offices of one kind or another); and even screeners refusing to believe that electronic devices without monitors, such as braille or synthetic speech computers used by persons who are blind, really are computers.

NCD believes that a further fact sheet or other authoritative guidance by the department dealing with these and other specific issues (including issues that may be highlighted by consumer complaints) and using examples drawn from reported experiences would go a long way toward making the principles of nondiscrimination clearer and more concrete and could accomplish a great deal toward achieving the goals of the earlier fact sheet.

Depending on what further consumer feedback a review of consumer complaints reveals, additional steps to raise the visibility and strengthen the enforcement of ACAA are needed. The Federal Aviation Administration (FAA) should consider adding a module on ACAA to the training that airport security personnel will be receiving under the new airport security legislation.

NCD also requests the DOT to report on the status of the other oversight and coordination initiatives mentioned above, again with a view to assessing their current status and immediate prospects, and to identify any additional resources, legislative support, or budgetary support that may be needed to carry them forward to successful completion

NCD is pleased to have worked closely with the DOT in connection with its ACAA implementation and enforcement efforts, including in the development of the fact sheet noted above. NCD and the DOT are currently involved in a number of additional initiatives that are expected to bear fruit in 2002. These initiatives include efforts to develop policies through industry/government/disability community consensus on standards for accommodating

passengers using service animals and on the availability of onboard medical oxygen for passengers who need this resource.

The mechanisms by which these initiatives have been advanced are in themselves important and worthy of broader use across the Federal Government. Several stakeholder forums and advisory groups have been created to bring representatives of the relevant constituencies, including people with disabilities, together and to develop consensus standards and statements on issues of concern. This approach should prove useful in a wide range of other regulatory, policymaking, and enforcement settings as a means of obtaining the best information and input and for ensuring the cooperation of all parties in the actions that result.

One additional ACAA-related issue remains to be addressed. During 2002, airport security screening practices and personnel will be brought under the direct control of the Federal Government. A new Transportation Security Administration (TSA) within the DOT has been established to manage airport security. To the degree that the enabling legislation and regulations for this program create consumer complaint mechanisms, questions of the interface between these protections and those arising under ACAA once again emerge. The DOT should move quickly to clarify the responsibility of the TSA in relation to ACAA and should take steps to resolve any uncertainties that may arise through the overlap between, or through differences between, the parallel complaint mechanisms now in existence.

2. ACCESSIBILITY OF INTERCITY BUSES

Pursuant to the Transportation Equity for the 21st Century Act (TEA-21),[107] the DOT has committed substantial multiyear resources to over-the-road bus (OTRB) accessibility. Last year, NCD enumerated these major commitments and commended the DOT for these initiatives. *NCD recommends that the DOT report on the status of these initiatives and on whether its and Congress's expectations for the accessibility of city-to-city fixed-route, rural, commuter, charter,*

and tour bus services are likely to be met within the applicable time frames, given the current pace of progress.

To the degree that bus operators receive capital and other federal assistance under these programs to meet accessibility requirements for their fleets and to satisfy related service requirements, *NCD also recommends that the department report on the compliance by participating bus operators, transit companies, and public transit authorities with all applicable legal requirements bearing on vehicle accessibility and on the provision of reasonable accommodation to customers with disabilities.* In particular, the department should report on the extent to which participating entities have put published procedures in place that describe their provision of necessary assistance and services to passengers with disabilities; the extent to which participating entities make these procedures known to customers; and the extent to which consumer feedback offers insight into the degree of compliance with these procedures in day-to-day operations.

If such data are unavailable, the DOT should undertake to collect and publish such information, including through use of techniques for obtaining consumer feedback of the kind that have been so effectively used in the air transportation area.

Even if the overall level of industry compliance with the goals and time frames of TEA-21 are regarded by the DOT as satisfactory, *NCD strongly recommends that the department authorize and enter into no further voluntary compliance agreements (VCAs) with any carriers.* The law is clear and by now well known. If carriers cannot comply, the law should be applied, and if carriers can comply, no justification exists for characterizing as voluntary what the law and regulations mandate, that is, enforcement action.

3. DOT-DOJ COLLABORATION

In its 1999-2000 status report, NCD commended the litigation efforts of the Department of Justice (DOJ) and urged it to initiate more intensive collaboration with the DOT to identify cases

of persistent noncompliance with transportation accessibility requirements warranting legal action against private bus operators, public transit authorities, and contract providers of service to public transit agencies. *Based on the outcomes of such cases as* James *in Raleigh, NC, and* Richardson[108] *in Steamboat Springs, CO, NCD recommends that the DOT and the DOJ report on the current status of the law with regard to the authority of the government to pursue remedies against bus operators who arguably discriminate against passengers with disabilities.*

Because settlements, consent decrees, or even court orders in transportation vehicle accessibility cases usually involve remedies that will be implemented over a number of years, *NCD recommends that the DOJ and the DOT jointly develop a system for ongoing monitoring of respondent performance, so that departures from agreed-on or court-ordered terms and timetables can be promptly identified and rectified.*

4. NEW FREEDOM INITIATIVE TRANSPORTATION PROPOSALS

As the DOT forges ahead with the implementation of TEA-21, the transportation-related requirements of Title II of the ADA, and other laws, it does so under changed circumstances resulting from the transportation initiatives contained in President Bush's New Freedom Initiative (NFI). The DOT should be alert and responsive to the issues of coordination, complementarity, and continuity involved in continuing to implement existing policy while embracing the innovations, demonstration projects, funding priorities, and other features of the NFI.

NFI includes major recognition of the role that barriers to accessible transportation play in the integration of persons with disabilities into society. Consistent with this awareness, the Administration's FY 2002 budget proposal included $45 million for pilot transportation accessibility projects and $100 million for transportation improvement matching grants. These funds were not included in the budget adopted by Congress.[109] *NCD recommends that Congress reconsider these funding requests and give the DOT such authority and resources as it may need to implement these two new programs on an innovative and inclusive basis.*

With respect to these and any other NFI proposals, *NCD recommends that the DOT encourage both pilot and competitive matching grant program applications from the broadest range of eligible entities.* It should be noted that programs are not a substitute for complying with ADA requirements. Beyond outreach to the broadest range of possible applicants, the DOT must endeavor to encourage the use of the widest possible variety of transportation modalities as well. To accomplish this, *NCD also recommends that the DOT does not implement these programs in ways that limit them to automobile transportation initiatives, but seek and respond to initiatives that include the use of other transportation modes.* Bearing in mind that different regions of the country and many communities make use of commuter rail, light rail, inland watercraft, and even subways as elements of their transportation strategy, the DOT should be receptive to proposals that attempt to bring innovation and improvement to all these modes of transit and, in so doing, should be maximally responsive to the needs and preferences of distinctive communities and local customs throughout our nation.

In evaluating proposals under the NFI programs, the DOT should further be mindful that whereas physical inaccessibility of transportation vehicles has historically been the major barrier to transportation equity for persons with disabilities, it is by no means the only transportation barrier these citizens face. Virtually every disability subpopulation has and continues to face obstacles to safe and reliable transportation, ranging from the inaccessibility of print-only maps, timetables, and signage to persons with visual impairments to the inaccessibility of announced-only delay or detour information to people with hearing disabilities to the continuing inaccessibility of many fare and ticket machines to persons with visual, cognitive, or motor impairments.

5. RESEARCH AND TECHNOLOGICAL INNOVATION

In many ways, transportation has changed less over the past fifty years than most other aspects of our lives. Nothing equivalent to the Internet for how we move information has emerged to revolutionize the way we move people. Nevertheless, recent advances in transportation technology—ranging from the global positioning systems and other remote guidance and

tracking systems to new designs in energy-efficient, high-speed scooters—have created exciting possibilities for increasing accessibility and independence for a host of travelers with disabilities.

New personal transportation vehicles, such as the Ginger, unveiled in December 2001, promise the long-delayed revolution in transportation, but by no means is it self-evident or automatic that these benefits and opportunities will be extended to Americans with disabilities. In order for such innovations to be responsive to the needs and concerns of people with disabilities, testing and evaluation efforts must be organized with a conscious intention to include people with disabilities in focus or experimental groups.

For that reason, the DOT should undertake efforts in conjunction with the National Institute on Disability and Rehabilitation Research (NIDRR) or other suitable entities to facilitate the innovative use of all such personal transportation vehicles and devices by persons with various disabilities and to ensure that the results of such experimental use are made known to the manufacturers of all such technology in a timely fashion so these findings can be incorporated into the results of beta or other prototype field testing. On the basis of input from users with disabilities, it may prove possible to implement at early stages design enhancements that would be difficult or impossible to retrofit once large-scale distribution and use occur.

6. PARATRANSIT

Anecdotal reports continue to abound about problems in the design and delivery of paratransit services throughout the country. Such problems include disproportionate investment of program resources in cumbersome and lengthy eligibility determinations at the expense of service delivery; arbitrary limitations on service based on time, location, purpose of trip, or other variables; denial of service to persons who, although physically capable of boarding and disembarking from fixed-route transportation vehicles, cannot safely or reasonably get from their homes to and from the stopping places for such vehicles; refusal to carry personal assistants or other companions; refusal to carry service animals; insistence on certain kinds of wheelchairs or

other mobility aids; imposition of service priorities based on the purpose of the trip; poor training and high turnover of personnel; failure to keep scheduled appointments or imposition of unreasonable advance notice requirements for scheduling trips; and other matters.

A particularly recurrent problem that calls for definitive guidance relates to the right of persons with visual disabilities to use paratransit services. Accounts from around the country indicate that while most systems recognize the eligibility of persons who are blind or have significant visual impairments, a large number of other transit systems take the view (apparently because the applicants in question can walk without difficulty) that this group of persons with disabilities is not eligible for paratransit services.

The DOT should ensure effective oversight of paratransit services and meaningful opportunities for the resolution of problems and for the redress of grievances. This is particularly so because many of the problems reported appear to involve disregard for or ignorance of existing regulations.

Similar to other components of the transportation system, paratransit services lend themselves to the kind of innovation contemplated by the NFI and other long-standing unfunded initiatives. In view of the widespread frustrations with paratransit services noted, the DOT must continue to monitor the system with vigilance, but the department must at the same time maintain the necessary flexibility to accommodate experimental projects, nontraditional providers, and new methods and technologies. If that is done, the best of existing paratransit practices and the promise of new approaches may be effectively merged and applied.

Chapter 11
Assistive Technology and Telecommunications

1. THE NEW FREEDOM INITIATIVE AND ASSISTIVE TECHNOLOGY

The president's New Freedom Initiative (NFI) places great emphasis on the development and deployment of assistive technology (AT). That emphasis includes major commitments to research through the National Institute on Disability and Rehabilitation Research (NIDRR), expansion of resources available for AT loans to individuals with disabilities under the Alternative Financing Program (AFP) of Title III of the Assistive Technology Act, and commitments to a number of innovative programs (such as use of technology to develop home-based entrepreneurship and employment opportunities), along with use of technology as a key element in the achievement of other policy goals (e.g., implementation of the *Olmstead* decision). *NCD welcomes these initiatives and recommends that the Administration continue taking the steps needed to ensure their fulfillment, including coordination of efforts among agencies with overlapping jurisdiction, ongoing provision of technical assistance to states and other partners, and clarification of applicable income tax rules and of Social Security income and resources limitations in order to avoid possible work disincentives that could interfere with the success of employment-oriented activities.*

a. COORDINATION

By coordination, we mean that the pro-AT efforts and activities of one program or agency should not be inadvertently undermined or negated by the policies or activities of another, especially when these barriers arise only as an incidental by-product of policies that were not developed with AT in mind. For example, the NFI proposes to increase home-based work opportunities for people with disabilities by, among other things, making the costs of computer equipment and telecommunications services provided to such persons tax deductible to the employers or other

third parties who furnish them. This is a promising proposal, but unless accompanied by changes in the rules governing a number of benefit programs, as well as changes in the tax law, it could actually result in a net reduction in the services available to persons with some of the most significant disabilities.

Unless the rules for Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) are simultaneously modified, small increases in income could result in more than offsetting curtailment of payments under these programs. Still worse, the services linked to these programs (including in-home Medicaid home health care or other services, even services necessary to permit the individual with a significant disability to perform gainful work at home) could also be jeopardized.

The unintended consequences of any policy initiative cannot readily be anticipated, but attention to coordination issues is required in the planning stage if such unforeseen barriers are to be fully avoided. NCD is pleased at early indications that the Administration understands this point. The recently released preliminary report outlining progress under President Bush's June 2001 *Olmstead* Executive Order contains a section on AT and demonstrates a recognition that meaningful progress in removing barriers to its use requires the coordinated and concerted efforts of a number of agencies and programs.

NCD believes that either the Interagency Committee on Disability Research (ICDR), which the Administration has proposed to reinvigorate with increased funding, or the newer Interagency Committee for Community Living (ICCL), which has not yet been made permanent, could serve as the forum for identifying and addressing these and the myriad other coordination issues that will arise in implementing the Administration's creative AT programs and strategies.

b. ALTERNATIVE FINANCING PROGRAM

The Assistive Technology Alternative Financing Program (AFP) has been widely hailed as a means by which people with disabilities can take greater control of their own lives. The FY 2002 federal budget contemplates large increases for this program, which operates under Title III of the Assistive Technology Act and, though authorized as early as 1994, was not funded until two years ago. Certain provisions of the current law threaten the growth and success of the AFP program, however.

AFP requires the provision of state matching funds as a condition for receipt of federal program funds. As states face steep fall-offs in their tax revenues and deteriorating budgetary situations, the feasibility of providing matching funds at expanded levels may be called into question. Whereas the current match requirement of $1 in state money to every $3 in federal money is not out of line with other federal-state programs, the growth of the program is nevertheless likely to be somewhat hindered because new money is required and in-kind contributions, including from private sector partners, may not qualify for treatment as a match under the current rules.[110] Accordingly, *NCD recommends that, at least until state tax revenues begin to climb again, the matching fund requirements of Title III be suspended or be modified to broaden the kinds of participation that will be acceptable to meet the match.*

c. RESEARCH

The NFI includes a significant commitment to AT research. In implementing this commitment, the Administration should make certain that the distinctness of, and the relationship between, AT and universal design are recognized and honored. Over the years, NIDRR has demonstrated a farsighted grasp of the importance of universal design through its sponsorship of conferences on the subject and by its support, pursuant to competitive grant award processes, of a number of rehabilitation engineering and research centers (RERCs) having universal or accessible design work as their primary objective.

Research priorities should therefore include not only the development of new devices but also such matters as the ability and flexibility of the AT service system to accommodate universally or accessibly designed products that are not expressly or uniquely designed for people with disabilities but that have features allowing them to be used by everyone, including people with disabilities (e.g., cell phones that allow hands-free operation); research into the implications for the economy of accessible design (in terms of the costs and benefits of up-front investment in accessible design of products and in terms of the proper allocation of such costs and benefits); research, based on the findings of the current Government Accounting Office (GAO) study,[111] to be conducted in conjunction with the Treasury into the viability of tax credits or other incentive measures to stimulate the design, production, and marketing of accessibly and universally designed products and services; and research into the implications for learning and for assimilation of information when it is enriched by presentation in accessible audio and video formats.

d. CARRYOVER INITIATIVES

During 2000, the Clinton Administration launched a number of AT-related initiatives. Although several of these have been effectively merged into, or superseded by, NFI initiatives, at least one is worthy of further exploration. The previous Administration directed the secretary of the Department of Health and Human Services (HHS) to convene an interagency task force on health care coverage of AT.[112] This task force was charged to study the role that Medicare and Medicaid currently play and should play in the coverage of AT devices. The work of the task force was intended to provide a framework for future Medicare and Medicaid coverage decisions that complement overall efforts to promote employment opportunities for people with disabilities. In the executive memorandum setting it up, the task force was directed to conduct a study on the role of Medicare and Medicaid in covering AT devices that encourage employment of individuals with disabilities. With these two health insurance programs receiving attention and recognized to be in need of modernization and reform, consideration of the role they should play in AT is all the more timely.

The recent *Olmstead* report issued by HHS includes some promising views and intentions regarding AT and identifies a number of barriers to AT provision and use in current law. The report does not indicate, however, any Administration plans to systematically evaluate the current and projected role of these two major health insurance programs as sources of funding for AT. Accordingly, *NCD recommends that the Administration add to its agenda a comprehensive study of what role the health care system should play in the provision, funding, and development of AT.*

2. IMPLEMENTATION OF SECTION 508

Section 508 of the Rehabilitation Act of 1998 (technically, Section 508 of the Workforce Investment Act [WIA] of 1998, because the Rehabilitation Act amendments were adopted as part of WIA) has been praised as the most far-reaching universal design statute ever enacted. This law provides that in their purchase and use of electronic and information technology (E&IT), federal agencies must adhere to the principles of "accessibility" to persons with disabilities. The law's purpose is to ensure that access to such technology—including computers, photocopiers, audio-visual training materials, and Web sites, to name some of the major types—is equal for federal employees and members of the public with and without disabilities. In those cases in which achievement of accessibility constitutes an undue burden, the agencies are not required to obtain accessible technology, but they are still required to develop alternative means for making information available to government employees or members of the public with disabilities.

As important as these provisions are in their own right, the greatest significance of Section 508 may lie in its across-the-board impact on the design practices of industry. If one of the largest customers for E&IT demands accessible products, efficiency will dictate that all such products are designed with accessibility principles in mind. Achievement of this long-term goal of reorienting mainstream design practices toward accessibility depends on the success of the Federal Government in implementing the new requirements. If Section 508 is not enforced, or proves unworkable or too costly, its leverage value will be lost. If the law proves effective and is

followed, the communications and information landscape can become an even greater force for democracy and participation than it already is.

a. IMPLEMENTATION

During the past year, important steps in the transformation of Section 508 from a statute to a part of daily life in the federal sector have taken place. On December 20, 2000, the Access Board issued final guidelines defining the key terms and requirements of the statute and operationalizing its requirements.[113] Subsequently, as required by the section, the Federal Acquisition Regulation Council (FARC) added regulations to the Federal Acquisitions Regulation (FAR) specifying how federal procurement officials in all covered executive branch agencies should apply the law.[114]

Section 508 has been fully in effect—both its civil rights and remedies provisions, which allow those alleging its violation to bring complaints, or even to file suit, against the offending federal agency, and its procedural provisions, which are those embodied in the FAR—since late June 2001. The law appears to have proceeded largely without incident. But whereas the earthquake that so many predicted—some hopefully and some with trepidation—has not occurred, several serious problems in the administration of the law have already come to light. Although no critical mass of experience or wealth of data under the statute yet exists, informally reported experience suggests a pattern that needs to be addressed if the law is to yield the full benefit its supporters expect.

The principal questions that have emerged thus far relate to the lack of adequate compliance monitoring. The DOJ is vested with responsibility under the law to make biannual reports to the president and Congress on the implementation of Section 508. To that end, the DOJ has on the one hand undertaken biannually to measure the performance of federal agencies in relation to the accessibility of their public and employee Web sites. On the other hand, no monitoring procedures are in place to determine the frequency with which agencies invoke the "undue

burden" defense or any of the several other exceptions to compliance authorized in the FAR. Nor are there any auditing procedures in place for evaluating the soundness of such undue burden claims by agencies.

Federal agencies are required to document the reasons for claiming undue burden with respect to any procurement or component of a procurement for which the claim is made, but no one is charged by the law to collect, review, or evaluate these claims. Anticipating this problem, NCD recommended in its June 2001 report *The Accessible Future*[115] that the General Services Administration (GSA) take measures to fill this potentially critical information vacuum. Accordingly, *NCD now reiterates its recommendation that the Administration institute procedures for collecting and tracking these undue burden claims.*

Additionally, because experience will reveal other unforeseen problems in the implementation of this law, the Administration needs to take measures to ensure its timely awareness of all emerging issues. To that end, the Administration should issue a Request for Information (RFI) to agency chief information officers (CIOs) and other interested parties, seeking comprehensive information on all problems, unforeseen vagaries, or subsisting uncertainties that have arisen thus far in the implementation of Section 508.

Because the RFI can present only a snapshot of 508 implementation at a particular moment in time, other means must be found to maintain the necessary level of oversight and feedback. The required DOJ biannual reports, if expanded in scope, may represent one source for keeping implementation information current. Accordingly, *NCD recommends that information on implementation and compliance issues be included in the DOJ's reports to the president and Congress.*

b. TECHNICAL ASSISTANCE AND OUTREACH

The GSA launched the Federal Information Technology Accessibility Initiative (FITAI) to help federal agencies provide access to E&IT and to meet the requirements of Section 508. This

program—involving, among other things, a major Web site (http://www.section508.gov) serving as a portal to a variety of 508-related information and resources—supports, through outreach and information sharing, the Federal Government's efforts to comply with the law. The government's 508 Web site also serves as a rich source of information for vendors wishing to sell to the government, for members of the public, and for other interested groups. One potential benefit of this ROI is the opportunity it would afford to learn from government information technology professionals, from vendors, and from consumers about how effective the www.section508.gov Web site has been in meeting their needs.

In last year's annual status report, NCD also recommended that the GSA ensure that tools for measuring relative accessibility and for evaluating vendor accessibility claims be created, validated, adopted, or adapted for all covered forms of E&IT. A number of excellent, Web-based tools exist to help webmasters, CIOs, and consumers evaluate the accessibility of Web sites and offer guidance in Web site repair when shortcomings are disclosed.[116] As such, it seems fair to say that today, though there will always be new situations and though some subjectivity necessarily goes into the determination of how to make particular Web-based information accessible, we know how to make Web sites accessible.

In the long run though, Web site accessibility should better be seen as a starting point than as an endpoint. As one recent study shows, accessibility does not necessarily denote a high degree of usability, and people with disabilities often require more time to complete Web-based tasks than other users do.[117] Evaluation tools, therefore, should be developed that concern themselves not only with the technical fulfillment of accessibility standards, as important as these are, but also with usability, defined in terms of the relative difficulty, accuracy, and time required for the accessing of Web-based information or the performance by persons with and without disabilities of interactive tasks on the Web.

When it comes to the variety of equipment and devices, hardware, and operating systems and applications software subsumed under Section 508, the problems associated with validating

vendor claims, with comparing the relative accessibility of competing products that approach accessibility in different ways, with "scoring" products in the competitive bidding process in which each meets some accessibility requirements but fails to satisfy others, and with testing equipment under realistic and challenging conditions before its acceptance—all these present difficult and as yet unresolved questions. A number of efforts are under way to develop and validate protocols and templates for equipment testing and for developing objective and replicable scoring techniques to be used by procurement officials. Pending the widespread availability of suitable instruments, *NCD recommends that, at the very least, rigorous testing by federal agencies of devices under realistic and real-time conditions is an indispensable element of the 508 process.* Though holding out no guarantees, federal agencies should require such testing before the acceptance of proffered E&IT.

If prototypes are tested under the conditions of their intended use, in the performance of the tasks for which they were procured, and in the networks and configurations in which they will need to operate, significant light can be shed on their accessibility and usability. Wherever possible, agencies should use the services of employees or consultants with disabilities who have knowledge of the equipment to help conduct these tests.

c. A TECHNOLOGY-BASED CIVIL RIGHT

Unlike Section 255 of the Federal Communications Act (discussed later), which does not include any private right for an individual to sue for its violation, Section 508 confers a right for federal employees or members of the public to file a civil rights complaint or to bring suit for its violation. The implications of this important new civil rights protection are discussed in detail in NCD's *Accessible Future* report. Here we mean only to suggest that the DOJ, in its biannual report, should track such complaints or suits. Likely, the number and types of any such suits will provide important insight into how well Section 508 is working in the field and will alert the Administration and Congress to any reforms or updates that may be needed.

In this connection, a fascinating conundrum must be noted. Owing to its role in collecting data about Section 508 compliance for its reports to the president and Congress, the DOJ is likely to have far more current information and firsthand knowledge about agencies' implementation of Section 508 than it typically possesses about their implementation of most laws. In some cases, as a result of information supplied to it by the agencies or through its own independent monitoring of a random sample of Web sites, the DOJ may have actual knowledge that a particular procurement or agency is substantially out of compliance with the law. At the same time, if a court action is brought against a federal agency for the violation of Section 508, the DOJ's responsibility is to defend that agency in court.

Under these circumstances, it would be useful for the DOJ to indicate to the federal agencies and to the public, both of which it ultimately represents, how it intends to handle these situations should they arise. Does the DOJ believe its possession of such knowledge would give rise to a conflict of interest in its defense of federal agencies? Does the department believe itself to have an affirmative obligation to disclose such information on noncompliance, or does it regard this obligation as triggered only when it is specifically questioned or asked to produce relevant documents? Does the DOJ believe that, by reason of its institutional status, knowledge held by one unit cannot be imputed to other separate, walled-off units?

d. TELECOMMUTING

In its NFI, the Bush Administration favors the use of telecommuting for federal employees where possible, and this includes employees with disabilities. As it relates to Section 508 (and to the related requirements of Section 501 dealing with discrimination and equal opportunity in federal employment), implementation of telecommuting options for government workers with disabilities may present a number of issues.

For telecommuting to work, in some cases it may prove necessary to install accessibility features at the employee's home. Section 508 does not on its face contemplate the furnishing of access

peripherals or specialized software to individuals for private use away from federal facilities, but where the employee's home becomes his or her place of work, logic and equality dictate that the necessary accommodations be provided.

3. DISTANCE LEARNING

Web-based education and distance learning have grown exponentially. Universities that would have looked disdainfully at the practice only a few years ago are now embracing it eagerly as a technique for attracting a broad range of busy students. During 2000, through a series of public hearings, the National Web-based Education Commission conducted an investigation of the key issues that surround the increasing use of the Internet for learning, including the necessity for ensuring that all learners have full and equal access to the capabilities of the Web. In December 2000, the Commission issued a report of its findings from two years worth of hearings and e-testimony.[118]

In last year's annual report, NCD acknowledged the work of the commission, especially its focus on the policy issues of "access and equity." NCD strongly encouraged Congress to use the commission's report for the next few years as a roadmap to guide congressional activity in key areas, such as distance learning, technology development and transfer, Internet and Web-oriented research, and e-commerce, to name just a few. *NCD now recommends that the Administration review the report, formally indicate its views concerning its findings and recommendations, and act to incorporate those recommendations in policy to the extent appropriate.*

4. THE E-RATE

The Federal Communications Commission (FCC) administers the "e-rate" program, as it is known, which is a program designed to make Internet access and telecommunications services more affordable for schools and libraries. The e-rate does this by subsidizing the rate these institutions pay for such services, partly through rate concessions that are available to a broad

range of eligible institutions and partly through competitive grants. Although available to help schools and libraries generally, the e-rate program is structured so that the highest level of subsidy goes to institutions in urban or rural areas with high levels of poverty, as evidenced by such indicators as the number of children qualifying for the free school lunch program.[119]

The e-rate program is perhaps the leading recent example of our nation's commitment to universal service in the telecommunications sector. This commitment (originally to universal telephone service) goes back to the Federal Communications Act of 1934 and over the years resulted in the establishment of lifeline and other programs to ensure basic phone access to economically disadvantaged individuals as well as in policies that facilitated the expansion of telephone service throughout our country and helped equalize the disproportionate costs of bringing such service to remote rural areas. But the principle of universal service faces new and complex challenges in our time. By enacting the e-rate as part of the Telecommunications Act of 1996, Congress and our nation expressed the view that this concept of universal service still has meaning in the age of the Internet.

Given the intent of the program to target the greatest benefits to the poorest areas and individuals, and given the historical backdrop of universal access against which the program is set, there can be no question that the e-rate program was intended to benefit students and library patrons with disabilities, just as much as anyone else. Whereas the question has not yet been decided by any court, this history and interpretations by the DOJ and the FARC of other provisions of the section lead almost inescapably to the conclusion that the e-rate program is covered by Section 508.

Nevertheless, application of this or other civil rights requirements on e-rate beneficiaries and grantees has thus far proved surprisingly difficult. For the first three years of the program's operation, e-rate discounts valued at about $6 billion were awarded to schools and libraries without any explicit requirements or requiring any assurances from them that accessibility would be provided to the telecommunications services funded with e-rate monies for people (students

and library patrons) with disabilities. Eventually, meetings between NCD and the FCC in 2000 resulted in the inclusion of a generic accessibility notice in e-rate applications.

NCD expected that this was the first step in a process that would rapidly lead to revision of the FCC's e-rate application form and Web site to incorporate specific requirements for assurances from schools and libraries that they will adhere to federal accessibility mandates. To the dismay of many, the additional regulatory notices and procedural steps necessary to make accessibility requirements explicitly applicable to e-rate subsidy recipients have not yet occurred. No measures designed to make accessibility a specific legal compliance issue or even to require assurances from recipient institutions regarding their awareness and intentions concerning accessibility have yet been taken.

If, on the one hand, the FCC believes for any reason that it lacks legal authority to apply the requirements of Section 508 (or those of Section 504) to e-rate recipients, it should say so. Then it could join with advocates in seeking congressional action to endow it with the necessary jurisdiction. On the other hand, if the commission regards itself as possessing the requisite authority to promulgate such regulations, it should proceed to do so without further delay. There is no excuse in the year 2002 for those who receive public subsidies, through surcharges paid on telephone use by all, for the benefit of all, to make the benefits of universal access available only to some. As long as people with disabilities pay the surcharges that fund the e-rate, it is unthinkable that they or their children should be denied its benefits.

5. SECTION 255

Section 255 of the Federal Communications Act, as added to the law by the Telecommunications Act of 1996, requires that providers of telecommunications services (such as local and long-distance phone companies) and manufacturers of telecommunications equipment and customer premises equipment (CPE) must make their products and services "accessible to" and "usable by" individuals with disabilities where it is "readily achievable" to do so. Guidelines defining

and applying the concepts and provisions of the law were jointly developed by the Access Board and the FCC, and were adopted by the FCC as regulations.[120]

Although we have only had about three years of experience implementing Section 255 and operating under the FCC's 255 regulations, that experience, coupled with the emergence of new technologies, has revealed two key problems in the administration of the current law. Both problems are believed to be within the FCC's power to correct, or at least to substantially influence, and both require urgent action if the goals of accessibility are to be attained.

a. ENFORCEMENT

The FCC has sole jurisdiction over enforcement of Section 255. No appeals from its decisions or lawsuits are permitted. The enforcement of the law lies solely within the commission's control. For that reason, the commission's enforcement practices and their results must be the subject of special scrutiny.

As a basis for enforcement, the Access Board and the FCC undertook production of a periodic market monitoring report (MMR). This survey of telecommunications services and CPE accessibility was designed to identify areas of progress and areas of difficulty and to help the commission and industry focus resources in those product and service areas where progress toward accessibility was limited or slow. After being published once, the MMR has not been issued again. Because the MMR was widely believed to be a useful tool and because the FCC has not expressed any public dissatisfaction with the process of preparing it or with the results of its publication, the failure to update and maintain this resource is regrettable.

NCD recommends that the FCC indicate whether it no longer believes the MMR to be a valuable information resource in its enforcement of Section 255 and, if it does believe the MMR to be inappropriate, to indicate how it proposes to gather broad-based compliance information. If the

commission regards the MMR as a viable tool, it should revive the regular publication of this report, in cooperation with the Access Board.

A related issue concerns pattern-and-practice oversight. NCD is not aware of the exercise of any such oversight jurisdiction on the commission's part. Rather, it appears that the commission relies almost entirely on consumer complaints as a basis for its enforcement of the law. This is an inadequate basis for exercising its statutory and exclusive responsibility.

No studies are known to exist measuring the extent of consumer awareness of Section 255. Without evidence that the law is widely known or understood, complaints are likely to be relatively few in number. Moreover, such complaints are not necessarily representative either of the nature or the scope of accessibility and usability problems encountered by telecommunications users and customers with disabilities.

As significant, the commission's approach to complaint handling may further discourage recourse to the Section 255 complaint process by consumers with disabilities. On balance, the commission appears to favor complaint resolution by negotiation between the parties over adjudication or investigation by its own staff. The commission leaves it to the complainant, after contact with the respondent service provider or manufacturer, to indicate whether he or she is satisfied or dissatisfied with the resolution, and if the complainant is satisfied, the commission takes no further action. The commission is not known to have entered a finding against any respondent in a 255 case, and it has never made clear exactly what sanctions it would impose.

Although reliance on the parties to settle complaints themselves is appropriate in many situations, it may not be the best strategy when the parties come to the table with such vastly unequal resources. Ordinary customers do not have the means for evaluating manufacturer claims that one or another access feature is "not readily achievable," nor does the customer have the technical information or capacity to know whether, when a manufacturer or service provider claims that a requested accessibility feature is not readily achievable, this contention is accurate

or is based on full knowledge of the state of current technology and research. Finally, as is more and more the case, where accessibility and usability barriers result from the complex interaction between equipment and network components, isolated consumers have no authority to bring manufacturers and service providers together to determine how the responsibility for resolving problems can be most effectively allocated between them.

Faced with these disparities of knowledge and power, and lacking active investigation or representation by the FCC, consumers are left in a position in which, as a practical matter, they must either accept whatever respondents offer or confront the likelihood of gaining no redress at all. How voluntary and how informed can complainant acquiescence really be under these circumstances? In many cases, such expression of satisfaction may result from just this perception or may at best mean nothing more than that a manufacturer or service provider was attentive and courteous.

Although application of Section 255 to the facts of any complaint is a highly individualized matter, certain provisions of Section 255 can be enforced without reference to consumer satisfaction or complaints. For example, the law requires manufacturers and suppliers to make certain product information, manuals, and other relevant materials available in accessible formats on request. Provision must also be made—on the box or otherwise—to inform consumers of the availability of these accessible formats. The FCC could conduct random spot checks of products in stores to ascertain whether this is being done.

Similarly, the law requires that companies covered by Section 255 designate points of contact for 255-related issues. For this purpose, the commission has developed a list of covered companies and their designated 255 contacts. Once again, spot checks should likewise be conducted, through calls to technical support and customer services lines and through e-mails to the designated 255 company contact officials, to determine whether these assignments have been maintained, whether the names and contact numbers are accurate, and whether help desk

personnel who deal with the public are aware of 255 and know how to channel 255-related questions or calls to the named individual.

Generally speaking, the FCC's approach to enforcement of Section 255 can only be described as passive. If the customers the law was intended to enfranchise and the companies it was intended to guide could play on a level playing field, such an approach might be acceptable. Where the role of technical information and legal acumen create enormous disparities in their levels of knowledge about key legal and factual matters or in their ability to have any overview of industry practices, such an approach is tantamount to nonenforcement. If unchanged, this approach will amount to agency nullification of a major civil rights law.

b. TELECOMMUNICATIONS VERSUS INFORMATION SERVICES

It may come as a surprise to some, but under the law, the term "telecommunications services" does not mean all the services provided to the public by phone companies or other telecommunications services providers. Strictly speaking, the term applies only to those traditionally regulated services that facilitate and carry voice communication from one point to another. Similarly, the requirement of Section 255 that CPE be accessible and usable refers only to those components of such equipment as are involved in the voice communication process. Other services, ranging from e-mail to high-speed data transmission, are labeled "information services" and are generally exempt from regulation.

Because of this distinction between categories of service and between the equipment items or components used to facilitate and carry each of them, Section 255 is in danger of becoming applicable to a progressively smaller and less relevant portion of the e-commerce, education, and employment-related activity conducted over, or supported by, the communications networks of our country. Section 255 is in jeopardy of becoming trivial and anachronistic, unless something is done to make it applicable to the equipment and services that people more and more depend on and use.[121]

Recognizing the devastating potential of this situation, the FCC, in its regulations implementing Section 255, asserted the right to broaden the definition of covered telecommunications services to include a more realistic range of activities and functions. Through creation and use of an "adjunct-to-basic services" category,[122] the FCC undertook to apply Section 255 to all the features and functions necessary to make and complete calls, including those that could be used for e-mail, fax, data ,and graphics transmission, as well as for the placing, transmission, and receiving of traditional voice calls.

Subsequent to the implementation of these Section 255 regulations, the FCC has sought input from industry and the public regarding the need for further broadening the scope of Section 255 in the information services arena.[123] What the commission will do with the information received remains uncertain.

NCD recommends that the FCC act quickly to apply Section 255 to those information services that have become critical and staple parts of America's information society. To do less would be the equivalent of condemning Americans with disabilities to travel by horse and buggy while the rest of the population speeds past in modern cars.

In the event the FCC determines that it lacks legal authority to extend the coverage of Section 255 to the services that most impact education, economic activity, and quality of life today, the commission should immediately make this view known and join with advocates to request that Congress grant it the necessary authority or otherwise amend the law to ensure that the term "telecommunications services" is given a viable meaning. Finally, *NCD recommends that Congress, in its consideration of telecommunications deregulation legislation,[124] ensure that existing civil rights protections under Section 255 (as well as those that may accrue from other laws) are not inadvertently jeopardized, confused with economic regulations, and held hostage to conflicts among the telecommunications and media industries.*

6. E-GOVERNMENT

Broadly speaking, the term "e-government" refers to the variety of services, activities, information resources, and citizen-government interactions that the government provides, conducts, or supports in whole or in part through the use of E&IT. Like e-commerce, e-government has grown rapidly at the federal and state levels, and has become either the modality of choice or, in many cases, the sole available modality for carrying out a growing array of governmental functions. In areas from telecommuting and agency Web sites to online tax return filing, e-government affects our lives and defines and structures our options more and more with each passing day.

Whereas some people, having real choice in the matter, undoubtedly actively opt to minimize their participation in e-government, even they are affected by it. But at least for them, less access to federal information and services is a consequence they choose to accept. For all too many others, including millions of Americans with disabilities, denial or restriction of access to the technologies and resources of e-government is not a matter of choice but a matter of exclusion and deprivation. For these Americans, the digital divide is an increasingly sinister and crushing barrier to education, economic self-sufficiency, and full participation in community and civic life.[125]

Away from the Internet, the issues are no less pressing. We would not think of opening a post office or a new federal building today that did not provide physical access for wheelchairs, yet we continue to encounter new examples of e-government, including at the state and local levels, that are more or less inaccessible to persons with disabilities. And even short of sophisticated e-government applications, even inaccessible "low-tech" continues to abound. For example, if directories and directional signage are available only in print, if one's turn to talk to an official is made known only by a name or number being called out by a digitized voice, if no assistance is offered in the completion of informational forms, or if questions are required to be answered verbally, all of which are common, people with disabilities inevitably suffer serious disadvantage

and exclusion. Technology, much of it now simple and routine, coupled with flexibility and creativity in the rules governing its use, can correct many of these situations, but if new technology continues to be deployed without due and timely consideration of all these users, only growing inequality and estrangement from government will result.

Another key fault line for e-government relates to the expectations the government holds for those who use E&IT on its behalf and with public funds. When the government partners with state, nonprofit, or for-profit private sector entities, it imposes a number of expectations on these partners. These expectations, of course, vary with the law under which the relationship exists and with the objectives of the partnership, but all contractors, grantees, joint venturers, and operating agents are generally expected to comply with civil rights laws. No one would tolerate discrimination by these partners on the basis of race, religion, or gender. Yet, when inaccessible E&IT is deployed, resulting in lesser opportunities for people with disabilities than for others, discrimination is certainly what occurs.

Where once it may have been plausible to say that unequal access, because unintentional or unavoidable, was not discriminatory, progress in access technology and widespread information on its availability and importance no longer allow regret to suffice. Whether or not it is actionable or culpable, the failure to at least evaluate accessibility options and costs can no longer be regarded as accidental.

Some may argue that imposition of accessibility requirements in all federal partnership relationships goes beyond the authority of the Federal Government. But what law exempts e-applications and e-activities and services from the coverage of civil rights laws?

Because of a number of technical issues—including variations among enabling and authorizing statutes creating the myriad relationships in question—the process of implementing e-civil rights, as mentioned earlier in this report, must begin with a DOJ assessment of the current scope of federal authority and responsibility in this area. To the degree that the DOJ finds imposition of

accessibility requirements on e-government partners to be legally permissible, agencies should be instructed and assisted to move forward on including appropriate notices and requirements in their regulations, bid solicitations, contracts, grants, and other instruments. To whatever extent various laws are found to permit the establishment of such requirements, the DOJ should work with NCD and other appropriate bodies to develop suitable guidelines for use by line agencies in exercising this important option.

7. THE INTELLECTUAL PROPERTY AND CIVIL RIGHTS CONFLICT IN CYBERSPACE

As early as 1931, provision was made in our law for the transcription of books into braille by the Library of Congress for distribution through a national library system to persons who are blind and, subsequently, also to people who have other reading disabilities. Most recently, the Copyright Act was amended in 1996 to allow for the reproduction of all published books in "specialized formats" by a variety of nonprofit organizations other than the Library of Congress National Library Service for the Blind and Physically Handicapped for use by persons with reading disabilities.[126] Various safeguards are included in the law to prevent its being used as a subterfuge for damaging the economic rights of copyright holders, including bans on the distribution of the material for money.

Notwithstanding the willingness of the publishing industry to accept this legislation, recent developments suggest that the relationship between the access rights of persons with disabilities and the intellectual property rights of copyright holders may no longer be so benign. Developments occurring in the past year suggest that the intersection between technology and law has created new issues.

Pursuant to the Digital Millennium Copyright Act of 1998 (DMCA),[127] the DOJ appears to have taken the position that copyright protection extends to software created for copying electronic documents into formats other than those prescribed by the producer. In one widely publicized case, Russian computer programmer Dmitry Sklyarov was prosecuted in this country for writing

and selling a program that allowed Adobe e-books to be copied into other formats not approved by the manufacturer. Without going too far into the complexities of the case, it is enough to note that by interpreting the DMCA as it did, the DOJ took the view that not only the informational content but also the format in which information is presented comes under the umbrella of intellectual property. Ominously, the term widely used for what the programmer did was interfering with the "access controls" that the producer had a legal right to establish and enforce. In fact, development and dissemination of this program that allowed Adobe e-books to be copied into other formats was alleged to constitute a criminal violation of the Copyright Act, as well as conspiracy under the federal criminal code.

Although the defendant in this case does not appear to have been primarily motivated by accessibility concerns, the program he developed was said to represent the most effective means for blind persons who use screen-readers to gain access to these e-books. By the same token, no indication exists that the DOJ would have considered Sklyarov's program legal, even if it had been intended to facilitate access and had been distributed without charge only to persons eligible for the Library of Congress program.

Under these circumstances, concern is warranted over whether the DMCA will be interpreted to allow a variety of activities done for the sake of access but potentially deemed violative of the new law. If the DMCA does not authorize the disregard of "access controls" for the sake of accessibility, especially where the alleged infringement represents the only means for rendering the text in a format that computer users with disabilities can access, what options does the law provide for customers with disabilities to access the e-books published in a proprietary format, such as Adobe's? It is one thing for the law to contain no requirements that e-books be made accessible. It is quite another when the refusal of an e-publisher to provide them in an accessible format is backed by the weight and sanction of the criminal law. It is comforting to assume that no one would ever be prosecuted under these circumstances, but, although comforting, is it necessarily true?

NCD recommends that the Library of Congress make a determination regarding the means, if any, by which electronic publications provided in inaccessible formats can legally be made accessible to individuals with disabilities. It may be that the "fair use" doctrine adequately covers such cases, but in the face of the expansive definition accorded to intellectual property rights in the electronic realm by industry and by federal criminal law enforcers, this important question cannot be left to guesswork.

8. WIRELESS ACCESS FOR USERS OF HEARING AIDS

NCD congratulates the FCC for its issuance in October 2001 of a notice of proposed rulemaking (NPRM),[128] under the authority of the Hearing Aid Compatibility Act of 1988 (HACA), which will signal the beginning of a full inquiry into the current potential for requiring that mobile phones be made compatible with hearing aids. The 1988 legislation had exempted mobile phones from the hearing aid compatibility requirements applicable to other phones but had instructed the FCC to periodically review this exemption in the light of changing technology. This NPRM will facilitate the development of a complete record of the technological, economic, and other dimensions of the subject.

NCD hopes and believes that it will thus prove possible for the FCC to determine that the exemption is no longer warranted and therefore take action to establish a meaningful timetable for bringing cellular phones into full compliance with the accessibility provisions that apply generally throughout the telephone system.

9. ASSISTIVE TECHNOLOGY ACT REAUTHORIZATION

Earlier in this chapter we discussed the program for AT loans that is prominently endorsed by the NFI. As noted, the AFP operates under Title III of the Assistive Technology Act of 1998, but equipment loans are not the only important activity supported by this legislation.

The AT Act—which had its origins in the Technology-related Assistance for Individuals with Disabilities Act of 1998, or the Tech Act as it is commonly called—also provides for the operation of state-based assistive technology programs that carry out a variety of advocacy, systems-change, technical assistance, information dissemination, public awareness, and other activities on behalf of AT at the state level. From their vantage point, these projects are uniquely positioned to participate effectively in policy debates at the crucial state level, and it is widely believed that they have played an instrumental role in bringing about the consideration or incorporation of AT into a wide variety of settings and decisions.

The AT Act had been scheduled to sunset at the end of FY 2001, but action late in the first session of the 107th Congress forestalled this by extending the program through September 30, 2002. With this reprieve, we must consider whether it should be reauthorized and what form any long-term reauthorization should take.

Congress is expected to hold hearings on the AT Act early in the 2002 session. NCD believes that the AT Act should be reauthorized. Without this statute, it is unclear who could perform the many valuable functions currently carried out by the state-based AT projects. It is also unclear what could replace the voice for AT and accessibility in the councils of state government that the AT Act projects represent.

The state AT projects have also been responsible for operating the loan funds favored by the Administration. Were these state AT programs not to continue, other alternatives for the operation and accountability of the loan programs would need to be identified.

In many areas, the experience and knowledge of the AT Act programs are unique and irreplaceable. Before we abolish these small but tremendously instrumental programs, we must be able to answer the question of who or what will take their place. NCD believes that in the absence of any entity or institution readily available to fulfill the roles played by these small programs at state level, the AT Act should be reauthorized.

Another part of the AT Act has involved the provision of funds to the state-based protection and advocacy (P&A) programs for AT work. These funds, though again small in amount, have facilitated the development of nationwide expertise on a variety of legal issues surrounding AT and have contributed to the development of important public policy and legal initiatives.

While the P&As derive their funds from a number of program sources, the AT Act is the only source that focuses on AT. Again, in the absence of any alternative resources willing and capable of taking their place in this work, Congress should preserve this valuable resource, which we believe yields far more than its minimal cost. Accordingly, *NCD recommends that P&A funding be continued as an element of the AT Act program.*

Chapter 12
International

1. INTERNATIONAL CIVIL RIGHTS

Early in 2001, NCD wrote to the secretary of state requesting that American foreign policy initiatives ensure protection of the civil rights of persons with disabilities.[129] Although respectful of other cultures, including those with values differing from our own, we believe that many legitimate opportunities exist within the framework of the variety of international aid and development programs, cultural exchanges, and bilateral and multilateral relationships we maintain to encourage the fullest possible inclusion of people with disabilities in all activities and benefits.

NCD appreciates that the State Department has been totally absorbed in other concerns of the most fateful sort during the final months of 2001.

In the experience of these recent months are strong indications of the wisdom of incorporating a strong civil and human rights commitment into the fabric of our nation's relations with, and outreach to, other lands. For reasons that need no repetition here, the treatment and the rights of women have become a centerpiece of our foreign policy to a degree as never before. We have come to understand that in the oppression of women and in the denial of their human rights, many unpleasant truths about other societies can be glimpsed, and we have learned that by pressing for recognition of the dignity of women, other benefits can result.

As it may relate to Afghanistan, NCD believes that many of the same truths, the painful and the hopeful alike, underscore the aspiration for equal rights and opportunity for people with disabilities. As that nation struggles to lift itself from the crushing burdens of the past twenty years of foreign occupation, civil war, and despotism, we hope that the values of such laws as Section 504 or Title II of the ADA can find their way into its new laws and practices.

Tragically, one enduring legacy of the past two decades is likely to be the presence of a significant number of people with disabilities in Afghani society. Any measures that facilitate the fullest participation of these individuals in society cannot help but be advantageous to reconstruction and to the future.

NCD believes that in due time, circumstances will be presented for NCD to resume its work with the State Department on behalf of the application of disability rights in a broad range of settings and under a number of programs. NCD also believes that it is necessary for the Council to render its assistance to the State Department to continue to craft a foreign policy that respects and advances all human rights.

2. UNITED NATIONS CONVENTION

On November 30, 2001, the United Nations General Assembly approved by consensus the Mexican resolution calling for the establishment of an ad hoc committee, open to participation of all member states and accredited observers, to consider proposals for a comprehensive international convention to protect and promote the rights and dignity of persons with disabilities.[130] In cooperation with the United States International Council on Disability (USICD), NCD co-sponsored a meeting in June 2002 that brought together disability and international human rights advocates to discuss the rationale for the convention and to explore the application of the future convention to the human rights of people with disabilities. NCD is proud to participate in this effort and looks forward to the development and eventual ratification of the proposed convention.

3. INTERNATIONAL DAY OF DISABLED PERSONS

The annual International Day of Disabled Persons ceremonies were held on December 7, 2001. President Vicente Fox of Mexico, the lead sponsor of the UN resolution described above, was honored. Also honored for their human and disability rights work were seven eminent American

women who served in the previous Administration and who continue to serve the cause of human and civil rights in a variety of capacities today. We know that members of the current Administration will in due course be honored for their share of accomplishments on behalf of these great causes.

Chapter 13

Homeland Security

From a term that would have evoked various interpretations and a great deal of puzzlement among the general public as recently as last summer, "homeland security" has emerged as a central concern of government and citizens and as a major component of national, state, and local budgets. In too many instances, NCD has learned of the emergence of assumptions and stereotypes of people with disabilities—for example, restricting the access of people with disabilities to lower levels of workplaces, places of public accommodations, and housing. In planning for how our nation will respond to contingencies that all hope will never occur, the presence among us of more than 50 million Americans with disabilities must not be overlooked or forgotten.

Experience in the grim and terrifying hours of September 11 illustrates many of the issues facing this segment of our population. People who were deaf often could not follow news reports on TV, because of the lack of captions. If life-and-death instructions were conveyed by the emergency warning broadcast system today, would their accessibility to people who cannot hear be ensured?

Evacuation plans for major buildings and facilities did not always include provisions to ensure that people with disabilities could have an equal chance of making it out. If a major facility had to be evacuated today, would occupants who are blind have the means of knowing the location of emergency exits? Would persons using wheelchairs know where to go or what to do if elevators were turned off? Would persons who cannot hear be alerted by visual alarms to the need for swift action? Would people with vocal communication disabilities be heard when rescuers searched for those in need of help?

Throughout this report we have discussed many issues bearing on equality of opportunity and equality of treatment. As the imperatives of domestic security and national preparedness make

more vividly clear than ever, these concerns are far from abstract. To put the matter in yet starker terms, if a nuclear facility were to be the target of terrorism and public health officials were to distribute potassium iodide to protect the populace against the effects of radiation, would people with disabilities know where to get it, have physical access to the distribution centers, be able to open the packages or seals, or be able to read the usage instructions? It is easy to say that someone would help them, would do it for them, but is that comforting expectation enough?

Let us learn from our tragedy and let us use our solidarity and shared sense of national purpose to ensure accessibility and equality, not only in our reaction to danger but as well in the pursuit of our hopes. The values we embrace and offer to others are not values for some. They are nothing if not values for all.

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Endnotes

1. Major NCD reports, recommendations, and policy analyses include *Toward Independence: An Assessment of Federal Laws and Programs Affecting Persons with Disabilities* (1986); *Meeting the Unique Needs of Minorities with Disabilities: Report to the President and the Congress* (1993); *Progress in Advancing the Status of People with Disabilities Around the World: The Work of the United States Delegation to the 33rd Session of the Commission for Social Development of the United Nations* (1993); *Sharing the Risk and Ensuring Independence: A Disability Perspective on Access to Health Insurance and Health-related Services* (1993); *Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities* (1993); *Inclusionary Education for Students with Disabilities: Keeping the Promise* (1994); *Making Health Care Reform Work for Americans with Disabilities: Summary Information on Five Town Meetings on Health Care Reform* (1994); *Disability Perspectives and Recommendations on Proposals to Reform the Medicaid and Medicare Programs* (1995); *Access to the Information Superhighway and Emerging Information Technologies by People with Disabilities* (1996); *Foreign Policy and Disability* (1996); *Guidance from the Graphical User Interface (GUI) Experience: What GUI Teaches about Technology Access* (1996); *Outreach to Minorities with Disabilities and People with Disabilities in Rural Communities* (1997); *Equality of Opportunity: The Making of the Americans with Disabilities Act* (1997); *Impact of the Welfare Reform Legislation on Legal Immigrants with Disabilities* (1997); *Assisted Suicide: A Disability Perspective Position Paper* (1997); *Grassroots Experiences with Government Programs and Disability Policy (1998); Reorienting Disability Research* (1998); *Access to Multimedia Technology by People with Sensory Disabilities* (1998); *Implementation of the National Voter Registration Act by State Vocational Rehabilitation Agencies* (1999); *Implementation Plan for Executive Order 13166: Improving Access to Services for Persons with Limited English Proficiency.*

2. P.L. 101-336, codified at 42 USC Sec. 12101 et seq.

3. Title I, 42 USC Sec. 12111.

4. Title II, 42 USC Sec. 12131.

5. Title III, 42 USC Sec. 12181.

6. 47 USC. Sec. 255 (currently available at http://www.fcc.gov/cgb/dro/telecom_language.html). Implementing regulations at 36 CFR. Part 1193 (currently available at http://frWebgate.access.gpo.gov/cgi-bin/get-cfr.cgi?TITLE=36&PART=1193&SECTION=1&YEAR=2001&TYPE=TEXT).

7. P.L. 105-220, Sec. 408(b), codified at 29 USC Sec. 794d (currently available at, among other Web sites, http:///www.access-board.gov/sec508/guide/act.htm). Guidelines and interpretive regulations are at 36 CFR Part 1194, and 48 CFR Parts 2, 7, 10-12, and 39 (currently available at http://www.section508.gov/docs/final9967A.doc).

8. See, e.g., http://www.w3.org.

9. The Bobby program was developed by the Center for Applied Special Technology (CAST) (the latest version of this tool can be reached through http://www.cast.org).

10. Fact Sheet: *Steps Taken to Ensure New Security Requirements Preserve and Respect the Civil Rights of People with Disabilities* (Office of the Assistant General Counsel for Aviation Enforcement Proceedings, and Aviation Consumer Protection Division, U.S. Department of Transportation October 29, 2001) (currently available at http://www.dot.gov/airconsumer/01-index.htm).

11. P.L. 101-431.

12. 47 USC Sec. 613 (b). Under the authority of the same section, the FCC has adopted rules requiring the provision of a specified number of hours of video description on network and major cable TV broadcasts. Video description (sometimes also called audio description or descriptive video) is the inclusion in breaks in the dialogue of spoken narration described the visual elements of the program. These rules are scheduled to take effect April 1, 2002. (FCC Docket MM 99-339.)

13. President Bush's statement announcing the New Freedom Initiative (NFI) (February 2001) (currently available at http://www.whitehouse.gov/news/freedominitiative/text/freedominitiative.html). Compare, *Investing in Independence: Transition Recommendations for President George W. Bush* (NCD, January 2001) (currently available at http://www.ncd.gov/newsroom/publications/bush.html).

14. P.L. 105-17, codified at 20 USC Sec. 1400 et seq.

15. The Developmental Disabilities and Bill of Rights Act, as amended, P.L. 106-402, codified at 42 USC Sec. 6000 et seq.

16. Social Security Act Title XIX, codified at 42 USC Sec. 1896 et seq.

17. The federal Rehabilitation Act of 1973, as most recently amended by Title IV of the Workforce Investment Act of 1998, P.L. 105-220, codified at 29 USC. Sec. 701 et seq.

18. The Assistive Technology Act of 1998, P.L. 105-394, codified at 29 USC Sec. 3011.

19. P.L. 103-218.

20. The Ticket to Work and Work Incentives Improvement Act of 1999, P.L. 106-170 (1999).

21. Executive Order 13217 (June 18, 2001).

22. *Delivering on the Promise: Preliminary Report of Federal Agencies' Actions to Eliminate Barriers and Promote Community Integration* (HHS 12stbastja) (available at http://www.hhs.gov/newfreedom/presidentrpt.html).

23. Summary Report of Priority Areas and Indicators for IDEA Focused Monitoring (October 2001) (currently available at http://spannj.org/priorityareas-indicators.htm). Also, Panel Discussion on Focused Monitoring: A Video Web Cast of the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS), October 9, 2001 (currently available at http://www.connectlive.com/events/osers).

24. *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (NCD 2001) (currently available at http://www.ncd.gov/newsroom/publications/privliges.html). Also, News Release, (NCD 01-318, January 3, 2001) National Council on Disability Acknowledges Surgeon General's Report on Children's Mental Health. Compare, Surgeon General's Conference on Children's Mental Health: A National Action Agenda (currently available at http://www.surgegeneral.gov/cmh/childreport.htm).

25. List of the five civil rights reports: *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act* (2000) (available at http://www.ncd.gov/newsroom/publications/promises_1.html); *Back to School on Civil Rights* (2000) (currently available at http://www.ncd.gov/newsroom/publications/backtoschool-1.html); *Enforcing the Civil Rights of Air Travelers with Disabilities: Recommendations for the Department of Transportation and Congress* (1999) (currently available at http://www.ncd.gov/newsroom/publications/acaa.html); *The Accessible Future* (2001)(currently available at

http://www.ncd.gov/newsroom/publications/accessiblefuture.html); *Reconstructing Fair Housing* (2001) (currently available at http://www.ncd.gov/newsroom/publications/fairhousing.html).

26. *Achieving Independence: The Challenge for the 21st Century* (1996) (currently available at http://www.ncd.gov/newsroom/publications/achieving.html).

27. *National Disability Policy: A Progress Report*, November 1999–November 2000 (NCD 2001, available at http://www.ncd.gov/newsroom/publications/progressreport2000.html).

28. See, e.g., the Hale article, available at http://www.bls.gov/opub/mlr/2001/06/ressum1.htm. Compare, the three reports issued by the Presidential Task Force on Employment of Adults with Disabilities (PTFEAD): *Recharting the Course, 1998 Report to the President* (currently available at http://www.dol.gov/_sec/programs/ptfead/rechart.htm); *Recharting the Course: If Not Now, When? 1999 Report to the President* (currently available at http://www.dol.gov/_sec/programs/ptfead/ifnotnow.htm); and *Recharting the Course: Turning Points, Third Report to the President, 1999* (currently available at http://www.dol.gov/_sec/programs/ptfead/2000rpt/index.htm).

29. See, e.g., The ADA Notification Act of 2000, HR 3590 (106th Cong. Second Session); S. 782 and HR 914 (107th Cong. First Session).

30. Progress Report, Note 27 supra.

31. *Sutton v. United Air Lines*, 527 US 471 (1999); *Murphy v. United Parcel Service*, 527 US 516 (1999); *Albertsons Inc. v. Kirkingburg*, 527 US 555 (1999).

32. *Board of Trustees of the University of Alabama v. Garrett*, 531 US 356 (2001).

33. *Olmstead v. L. C.* 527 US 581 (1999).

34. *Ex Parte Young*, 209 US 123 (1908).

35. The Supreme Court in *Garrett* (531 US at 374) recognizes the distinctions arising from jurisprudence under *Young*, but the key question is what will happen when a suit, though nominally for prospective, nonmonetary relief, comes along, if that relief requires the state to spend money.

36. *Promises to Keep*, Note 25 supra.

37. The Department of Justice's quarterly reports on enforcing the ADA are available through the department's ADA home page at http://www.usdoj.gov/crt/ada/adahom1.htm.

38. The DOJ'S amicus briefs in *Pallozzi v. All State Life Insurance*, 198 F. 3d 28 (2d Cir. 1999), amended and rehearing denied en banc (204 F. 3d 392 2000); *Leonard F. v. Israel Discount Bank of New York*, 199 F. 3d 99 (2d Cir. 1999); and *Hooks* (Docket No. 9950891, 5th Cir. 2000, unpublished opinion) (amicus brief currently available at http://www.usdoj.gov/crt/briefs/hooks.htm). NCD has also filed amicus briefs in the Supreme Court in major cases, including *Toyota Motor Mfg., Kentucky v. Williams*, decided in favor of the employer in January 2002, which addresses the criteria for determining who is entitled to request reasonable accommodations from an employer under Title I of ADA (brief available at http://www.ncd.gov/newsroom/publications/toyota_amicus.html).

39. Apart from judicial advocacy, the state of Minnesota has waived its 11th Amendment immunity by statute. (Minn. Laws of 2001, can. 159).

40. Compare, NCD amicus brief in the Supreme Court in *Garrett* (currently available at http://www.ncd.gov/newsroom/publications/amicus_99-1240.html).

41. 29 USC Sec. 794.

42. See NCD's *Position Paper on Genetic Discrimination Legislation* and *Principles for Genetic Discrimination Legislation* (March 4, 2002) (currently available at http://www.ncd.gov/newsroom/publications/geneticdiscrimination_positionpaper.html).

43. The Voting Rights for the Elderly and Handicapped Act, P.L. 98-435 (1984).

44. Currently available at http://www.ncd.gov/newsroom/publications/electionreform.html. Compare, *Voters with Disabilities: Access to Polling Places and Alternative Voting Methods*, (U.S. General Accounting Office, 10staestja; GAO-02-107) (currently available at http://www.gao.gov/new.items/d02107.txt).

45. HR 3295 (107th Cong. First Session). Compare, Inclusive Federal Election Reform (NCD Web site) (currently available at http://www.ncd.gov/newsroom/publications/electionreform.html).

46. 2 USC Sec. 1302 (b).

47. Interim Section 102 (b) Report: *Electronic Information Systems Review and Report on the Applicability to the Legislative Branch of Section 508 of the Rehabilitation Act of 1973 as Amended* (U.S. Cong., Office of Compliance 11stacstja) (currently located at http://www.compliance.gov/images/section508.pdf).

48. *Carrying On the Good Fight: Summary Paper from Think Tank 2000—Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures* (2000) (currently available at http://www.ncd.gov/newsroom/publications/think2000.html).

49. RSA's award of a $2.5 million grant for the establishment of the National Technical Assistance Center for Asian Americans and Pacific Islanders, at the University of Hawaii Manoa, was announced December 14, 2001, in a release from disabilitydirect—announcement at www.disabilitydirect.gov. The name and citation given to the 1999 Asian Americans and Pacific Islanders Executive Order.

50. *Lift Every Voice: Modernizing Disability Policies and Programs to Serve a Diverse Nation* (1999) (currently available at http://www.ncd.gov/newsroom/publications/lift_report.html).

51. *Kimel v. Florida Board of Regents*, 528 US 62 (2000).

52. *Buckhannon Board and Care Home Inc. v. West Virginia Department of Health and Human Resources*, 532 US 598 (2001).

53. *West Side Mothers v. Haveman*, 133 F. Supp. 2d 549 ED Mich. 2001) (appeal pending in the Seventh Circuit).

54. After this report was drafted but prior to its publication, the Sixth Circuit ruled in May 2002 in favor of West Side Mothers in rejecting the argument that sovereign immunity shields state officials accused of depriving citizens of a federal right.

55. *Alexander v. Sandoval*, 531 US 1049 (2001).

56. See *The Sandoval Ruling* (August 17, 2001) (currently available at http://www.ncd.gov/newsroom/

publications/sandoval.html), an analysis developed by Professor Robert L. Burgdorf, Jr. for NCD on the U.S. Supreme Court decision in *Alexander v. Sandoval* and its implications for key disability rights laws.

57. NCD letter of November 8, 2001, to the assistant attorney general for civil rights (currently available at http://www.ncd.gov/newsroom/correspondence/boyd_11-08-01.html#main).

58. DOJ Supreme Court amicus brief in *Chevron Inc. v. Echazabal* (currently available at http://www.usdoj.gov/osg/briefs/2001/3mer/1ami/2000-1406.mer.ami.html).

59. After this Report was drafted but prior to its publication the Supreme Court decided in favor of Chevron. NCD's next progress report will report on this and other Supreme Court decisions involving the ADA.

60. Letter from NCD to the U.S. solicitor general, August 29, 2001 (currently available at http://www.ncd.gov/newsroom/correspondence/olson_8-29-01.html#main).

61. It may be that the DOJ'S role in this case, supporting a rule promulgated by the EEOC, reflects an administrative consideration or an interagency responsibility that supersedes the department's view on the merits of the case.

62. HR 1 (107th Cong. First Session), enacted as P.L. 107-110.

63. Progress Report, Note 27 supra..

64. H. Rep. 107-334 (107th Cong. First Session, December 2001).

65. *Back to School on Civil Rights*, Note 27 supra. Also, NCD's IDEA reauthorization white paper (currently available at http://www.ncd.gov/newsroom/reauthorizations/idea/idea.html). See also http://spannj.org/priorityaeas-indicators.htm. Also, *Summary Report of Priority Areas*, Note 23 supra.

66. Released October 3, 2001 (currently available at http://www.whitehouse.gov/news/releases/2001/10/20011003-1.htm).

67. Testimony of Secretary Rod Paige before the House Committee on Education and the Workforce regarding the Overidentification of Minority Students Under the Individuals with Disabilities Education Act, October 4, 2001 (currently available at http://www.ed.gov/speeches/10-2001/011044.html).

68. Note 63 supra.

69. Progress Report, Note 27 supra.

70. Id.

71. NCD letter to the chair of the Senate Finance Committee, April 18, 2001 (currently available at http://www.ncd.gov/newsroom/correspondence/grassley-4-18-01.html`#dmain).

72. Position Paper on Patients' Bill of Rights (March 30, 2001) (currently available at http://www.ncd.gov/newsroom/publications/patientsbillofrights.html). Also, Testimony of Marca Bristo, *Society's Great Challenge: The Affordability of Long-Term Care, submitted to the Senate Committee on Finance* (April 18, 2001) (currently available at http://www.ncd.gov/newsroom/testimony/bristo_4-18-01.html).

73. See also NCD's *Position Paper on Patients' Bill of Rights Legislation* (March 30, 2001) (currently available at http://www.ncd.gov/newsroom/publications/patientsbillofrights.html).

74. *From Privileges to Rights*, Note 24 supra.

75. P.L. 106-515.

76. HR 2260/S. 1272 (106th Cong. Second Session 2000).

77. Note 1, supra.

78. CIM 60.9. same citation to the CMS decision rescinding the AAC national coverage decision.

79. *Olmstead v. L. C.*, 527 US 581 (1999).

80. *Delivering on the Promise*, Note 22 supra.

81. Disability Rights Education and Defense Fund (DREDF) press release of August 27, 2001, announcing denial by federal district judge of motion by defendant's to dismiss suit by independent living advocates against rebuilding of hospital (available at http://www.dredf.org/press_releases/laguna.html).

82. Transition and Post-School Outcomes report, Note 1 supra.

83. Progress Report, Note 25 supra.

84. Executive Order 13078 (March 13, 1998), Section 2 (h) as amended October 25, 2000.

85. U.S. Department of Labor, Office of Disability Employment Policy, press release, October 1, 2001. Lists of grant categories and grantees are included (available through http://www.dol.gov/dol/odep/public/media/press/).

86. *Keeping the Promise*, Note 25 supra.

87. TWIIA, Note 20 supra. (Information on the status of the TWIIA program is available at http://www.ssa.gov/work/ticket/ticket.html).

88. Further information on the Medicaid infrastructure grants is available at http://www.hcfa.gov/medicaid/twwiia/infrastr.htm`#;d.

89. The OPM reasonable accommodation suggested language interim rule is currently available through www.opm.gov/fedregis/index.htm.

90. P.L. 105-220.

91. For an illustration of one well-intentioned effort by a federal agency, in this case the FCC, to grapple with these legal complexities, consider the FCC Report and Order on Docket Nos. 98-204 and 96-16 (currently located at http://www.fcc.gov/Bureaus/Mass-Media/Orders/2000/fcc00020/pdf).

92. Internal Revenue Code (IRC) Sec. 44, codified at 26 USC Sec. 44.

93. 26 USC Sec. 190.

94. 26 USC Sec. 51.

95. 26 USC Sec. 67 (d).

96. P.L. 104-193. Also, *Indicators of Welfare Dependence*, Annual Report to Congress by the Department of Health and Human Services (March 2001) (currently available at http://aspe.hhs.gov/hsp/indicators01/index.htm). Also, fact sheet: *Welfare Reform: Implementing The Personal Responsibility and Work Opportunity Reconciliation Act of 1996* (currently available at http://www.hhs.gov/news/press/2001/pres01/fswelre=m.html).

97. See http://www.hud.gov/reform/strategicplan.pdf, pages 28 and 45, about homeownership disparities. See also, http://www.huduser.org/publications/pdf/brd/04Gabriel.pdf.

98. *Delivering on the Promise*, Note 22 supra.

99. *Reconstructing Fair Housing* (NCD 2001) (currently available at http://www.ncd.gov/newsroom/publications/fairhousing.html).

100. Fair Housing Act of 1968, 42 USC Sec. 3601.

101. The Fair Housing Amendments Act of 1988, P.L. 100-430.

102. NCD letter to the secretary of HUD, November 21, 2001 (currently available at http:/ www.ncd.gov/newsroom/correspondence/martinez_11-21-01.html).

103. The HUD accessibility survey.

104. For example, HR 421 and HR 674 (107th Cong. First Session).

105. The Wendell H. Ford Aviation Investment and Reform Act for the 21st Century (AIR-21 Act) of 2000. Progress Report, Note 27 supra.

106. Fact Sheet, Note 10 supra.

107. TEA-21, the Transportation Equity Act for the 21st Century. Progress Report, Note 27 supra.

108. *James v. Peter Pan Transit Management Inc.* (EDNC) and *Richardson and Steele v. City of Steamboat Springs Colo.* (D. Colo.) (cases in which the DOJ has intervened to support the accessibility rights of public transit users). For further discussion, see Progress Report, Note 27 supra.

109. Press release, distributed by Justice For All, December 11, 2001 (currently available through http://www.jfanow.org).

110. Correspondence among NIDRR, state AFP grant recipients, and the national technical assistance provider, indicating NIDRR's views regarding will and what will not qualify as a match under the program.

111. P.L. 106-170 Sec. 303 (1999). The study was launched in late 2001 and results are expected in 2002.

112. Progress Report, Note 27 supra.

113. Access Board guidelines, Note 7 supra

114. Federal Acquisition Regulation (FAR), Note 7 supra.

115. *The Accessible Future* (NCD 2001) (currently available at http://www.ncd.gov/newsroom/publications/accessiblefuture.html).

116. Note 8, supra.

117. *Web Obstacles Abound*, Federal Computer Weekly (October 22, 2001) (summarizes research findings of Jakob Nielsen regarding costs and difficulties associated with the existence of Web sites that, although meeting legal accessibility requirements, are not readily usable) (currently available at http://www.fcw.com/fcw/articles/2001/1022/Web-access-10-22-01.asp).

118. Progress Report, Note 27 supra.

119. P. L. 104-104 Sec. 708.

120. Note 6, supra.

121. Preamble to Section 255 implementation guidelines, 36 CFR. Part 1193 (currently available at http://www.access-board.gov/telecomm/html/telfinal.htm).

122. Id.

123. The possibility that Section 255 would apply only to a comparatively narrow range of telecommunications activities was not discussed during the congressional deliberations over inclusion of civil rights protections in the Telecommunications Act. It came as a shock to many advocates.

124. For example, HR 1542 (107th Cong. First Session 2001).

125. Gould, Martin. *Building an Inclusive E-government Agenda for All Americans* (*in press,* Mary E. Switzer Seminar Monograph). Compare, S. 803 and H. Res. 2458 (107th Cong. First Session).

126. Interestingly, this change in the law enabled qualifying nonprofit membership and service organizations to make such copies without securing permission from the copyright holder. However, large print was excluded from the definition of specialized formats, presumably because there is a commercial market for large print materials.

127. The Digital Millennium Copyright Act of 1998 (DMCA), P.L. 105-304.

128. FCC Notice of Proposed Rulemaking (NPRM), November 14, 2001, In Re: Section 68.4 of the FCC's Rules Governing Hearing Aid-compatible Telephones (especially statement of Commissioner Abernathy).

129. NCD letter to the secretary of state, February 12, 2001 (currently available at http://www.ncd.gov/newsroom/correspondence/cpowell-2-12-01.htm).

130. NCD Bulletin (December 2001) (currently available at http://www.ncd.gov/newsroom/bulletins/1201.html).

PART II

Major Activities Summary—Fiscal Year 2001

The National Council on Disability (NCD) continues to be a leader in the development and analysis of disability civil rights policies that affect 54 million Americans with disabilities and their families. With a budget authorization of $2,615,000, NCD conducted a large array of activities in fiscal year (FY) 2001. Those activities promoted policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability, from all cultural backgrounds. They also helped individuals with disabilities realize the promise of the Americans with Disabilities Act (ADA) by empowering them to achieve economic self-sufficiency, independent living, inclusion, and integration into all aspects of society.

In FY 2001, NCD continued to review and evaluate new and emerging policy issues that have an impact on people with disabilities. NCD continued to identify the overall needs and concerns of people with disabilities by conducting hearings, forums, and conferences throughout the country and by responding to thousands of telephone, e-mail, and written inquiries on ADA and other disability civil rights issues.

NCD also continued its Disability Civil Rights Monitoring Project by completing research and comprehensive reviews of the first 12 years of enforcement efforts under the 1988 Fair Housing Amendments Act and related legislation and of the first 27 years of enforcement efforts under Section 504 of the Rehabilitation Act of 1973, as amended.

Also during this fiscal year, NCD began research on the implementation of the Civil Rights of Institutionalized Persons Act of 1980 and the landmark U.S. Supreme Court decision in *Olmstead v. L.C. 527 U.S. 581*. Both studies are part of NCD's series of reports known as Unequal Protection Under Law.

The Disability Civil Rights Monitoring Project, or Unequal Protection Under Law series, grew out of NCD's 1996 national policy summit, at which more than 300 disability community leaders from diverse backgrounds called on NCD to work with federal agencies to develop strategies for greater enforcement of existing disability civil rights laws. On March 18, 1999, NCD produced its first report, *Enforcing the Civil Rights of Air Travelers with Disabilities*. The second report, *Back to School on Civil Rights*, on the enforcement of the Individuals with Disabilities Education Act, was issued on January 25, 2000. The third report, *Promises to Keep: A Decade of Federal Enforcement of the Americans with Disabilities Act*, was released on June 27, 2000. The fourth report, *The Accessible Future*, was issued on June 21, 2001. The enforcement reports to follow in this series will be on the Fair Housing Amendments Act of 1988 and Section 504 of the Rehabilitation Act. They will be released in FY 2002.

Major activities for FY 2001 also included the release of several other publications that include *The Accessible Future, National Disability Policy: A Progress Report, Position Paper on the*

Patients' Bill of Rights Legislation, *Inclusive Federal Election Reform*, *Applied Leadership for Effective Coalitions*, and *Investing in Independence: Transition Recommendations for President George W. Bush*.

NCD also established a Cultural Diversity Advisory Committee, which provides advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. Specifically, the committee will help identify issues, expand outreach, infuse participation, and elevate the voices of underserved and unserved segments of this nation's population. This will help NCD develop federal policy that will address the needs and advance the civil and human rights of people from diverse cultures.

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ACTIVITIES FOR FY 2001

NCD conducted a variety of activities in FY 2001 that significantly increased consumer input into public policy issues affecting people with disabilities and provided information on NCD's daily operations. A summary of those activities follows.

NCD Sponsors International Conference
October 20–26, 2000

NCD joined the Social Security Administration in sponsoring the International Disability Law and Policy Conference held in Washington, D.C. Other federal sponsors included the Presidential Task Force on Employment of Adults with Disabilities; the President's Committee on Employment of People with Disabilities; the Department of State; the Department of Health and Human Services, Center for Mental Health Services; the U.S. Agency for International Development; the U.S. Information Agency; and the Department of Education, Office of Special Education and Rehabilitative Services.

During the five-day conference, more than 130 international disability law and policy subject-matter experts from more than 40 countries discussed legal theories, practical implementation issues, and strategies to advance or implement laws and policies to protect people with disabilities from discrimination and exclusion. One important outcome of the conference was broad support for an international convention on the human rights of people with disabilities.

NCD Updates Web Site
November 22, 2000, Washington, D.C.

NCD added three new features to its award-winning Web site (www.ncd.gov) that will help people with disabilities and those with limited English proficiency (LEP). One of the biggest challenges on the Web is finding what you are looking for. To help users find information more quickly, NCD has added a Netscape Web Publisher search function. This search function will allow users to quickly pinpoint specific information anywhere within the NCD Web site. Users can search through NCD documents for a specific word, obtaining search results that list all documents that match the query. Users can then select a document from the list to browse in its entirety. This function provides easy access to server content.

To help people with LEP, NCD has added a language translation function. Known as Babel Fish, this automatic translation service removes language barriers across the World Wide Web. Babel Fish translates to and from English, French, German, Italian, Portuguese, and Russian.

A list of frequently asked questions (FAQs) was also added to the NCD home page to help users answer standard questions about NCD, its mission, and the availability of disability resources.

NCD Seeks Research Contractors
December 20, 2000, Washington, D.C.

NCD published two requests for proposal (RFPs) in *Commerce Business Daily*. The first sought an independent contractor to develop and conduct a study evaluating the extent to which people with disabilities living in institutions are being served consistent with the Civil Rights of Institutionalized Persons Act and the Americans with Disabilities Act. The study will analyze data on institutional practices from a sampling of state institutions (varying from those with best practices to those with documented violations) to present findings about existing practices, assess compliance, and make recommendations for improving the quality of life and safeguarding the human and civil rights of people with disabilities who live in institutions. Findings and recommendations from this study will be a point of reference for NCD's study evaluating states' implementation of the *Olmstead v. L.C.* Supreme Court decision, which gave people with disabilities the legal right to choose community-based support options over institutional living.

The second RFP sought an independent contractor to develop and conduct a study of current strategies (including NCD's *Closing the Gap: Ten-Point Strategy for the Next Decade of Disability Civil Rights Enforcement* (www.ncd.gov/newsroom/publications/gap.html) for the swift and effective implementation of the 1999 Supreme Court decision in *Olmstead v. L.C.* This decision mandated a systemic change having major impacts for national and state-funded residential options for people with severe physical and mental disabilities. Despite a January 2000 directive to states from the Health Care Financing Administration strongly encouraging timely implementation, recent research indicates that the pace of progress is very slow in many states. The study will identify barriers to community placement and include recommendations for their removal.

NCD Welcomes New Members
January 3, 2001, Washington, D.C.

On January 3, President Clinton made two recess appointments to NCD. NCD said goodbye to outgoing member Shirley W. Ryan, who made numerous contributions to the empowerment of people with disabilities, especially in the areas of youth and the Individuals with Disabilities Education Act (IDEA). NCD member Michael Unhjem was also replaced. NCD welcomed new members Edward Correia of Bethesda, Maryland, and Gerald S. Segal of Haverford, Pennsylvania.

NCD Submits Transition Recommendations to President Bush
January 17, 2001, Washington, D.C.

On February 1, President George W. Bush released his New Freedom Initiative (www.whitehouse.gov/news/freedominitiative), which lays out a blueprint to increase investment in and access to assistive technologies and a high-quality education and to help integrate Americans with disabilities into the workforce and into community life.

NCD presented the Bush Transition Team with a copy of NCD's disability policy plan titled *Investing In Independence: Transition Recommendations for President George W. Bush.* (www.ncd.gov/newsroom/publications/bush.html). The document was provided to assist with transition efforts that involve disability policy. President Bush's New Freedom Initiative provides opportunities for the necessary changes to occur through the implementation of a coordinated, informed transition plan. NCD has, over the past several years, issued numerous civil rights evaluations and disability policy reports directly related to the areas articulated in the New Freedom Initiative. In submitting its transition recommendations, NCD offered its expertise and wealth of collective grassroots experience to help President Bush at the outset of his new administration and beyond.

NCD Conducts Community Briefing
February 6, 2001, Myrtle Beach, SC

NCD conducted a community briefing for people with disabilities that focused on NCD's latest findings and recommendations on federal disability civil rights laws.

NCD Publishes Applied Leadership for Effective Coalitions
February 14, 2001, Washington, D.C.

NCD published *Applied Leadership for Effective Coalitions* (www.ncd.gov/newsroom/publications/appliedleadership.html), which was designed to cultivate leadership development and coalition building across diverse cultures and disabilities with the hopes that we will continue to find common ground. The need for this guide grew out of an NCD-sponsored meeting among people from diverse cultures in May 2000.

NCD Releases Position Paper on Election Reform
March 15, 2001, Washington, D.C.

NCD released a position paper on *Inclusive Federal Election Reform* (www.ncd.gov/newsroom/publications/electionreform.html), which contains recommendations to effectively address the broad range of issues related to voting accessibility for people with disabilities and to develop strategic actions at the national level.

Disability Community Mourns the Loss of Rae Unzicker
March 22, 2001, Sioux Falls, SD

Rae Unzicker, a longtime disability civil rights advocate and beloved member of NCD since 1995, died at her home in Sioux Falls, South Dakota. She was 52. Her work on behalf of people with psychiatric disabilities is internationally known. NCD's 2000 report *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves* (www.ncd.gov/newsroom/publications/privileges.html) was the brainchild of Rae Unzicker. She

was a passionate speaker who wrote articles and made appearances on numerous television talk shows. Her contributions were significant. We will miss her dearly.

NCD Announces Third Fellowship
March 1, 2001, Washington, D.C.

In 1999, NCD established the National Disability Fellowship Program in Washington, D.C., to identify and develop new leaders with disabilities to enhance NCD's policy capacity. NCD began accepting applications for the third appointment, which will begin January 7, 2002.

NCD Releases Patients' Bill of Rights Position Paper
March 30, 2001, Washington, D.C.

NCD released its *Position Paper on Patients' Bill of Rights Legislation* (www.ncd.gov/newsroom/publications/patientsbillofrights.html).

As part of its health care agenda, NCD has long supported the enactment of a comprehensive and enforceable patients' bill of rights. In its 1996 report *Achieving Independence* (www.ncd.gov/newsroom/publications/achieving.html), NCD asserted that "all managed care plans, including those that serve only privately insured persons, should be required to meet federal standards to ensure access to specialty care, adequate grievance and appeals procedures, and equitable utilization review criteria."

People with disabilities and chronic illnesses are often high users of health care services and devices and thus are a litmus test for assessing the effectiveness of patients' rights legislation. In other words, if a patients' bill of rights protects people with disabilities, it is bound to adequately protect the rights of all health care consumers.

NCD has identified the aspects of a patients' bill of rights that are most important to people with disabilities and chronic illnesses. NCD does not endorse any specific legislation. Rather, NCD supports any approach that meets the principles that are identified and described in this document. NCD's hope is that members of Congress and their staff, other federal and state policymakers, and people with disabilities view this position paper as a valuable tool as Congress continues to debate this important issue,

NCD Participates in Air Carrier Access Act Conference
May 3, 2001, Washington, D.C.

NCD participated in a U.S. Department of Transportation–sponsored forum on "Working Together to Improve the Air Travel of Passengers with Disabilities." The purpose of this invitation-only forum was to provide disability community organizations, representatives of the airline industry, airport authorities, airport associations, and government officials, including officials from the Federal Aviation Administration and NCD, an opportunity to exchange ideas

and start a dialogue that will enable all parties to work together to better understand the needs of travelers with disabilities and explore ways of making accessible air travel a reality for all.

NCD Makes Hill Visits
May 2, 2001, Washington, D.C.

NCD members and staff visited various congressional offices to educate members of Congress and staff about NCD's activities.

Congressional Accountability Act
May 10 and 31, 2001

NCD met with the staff of the Office of Compliance, which was established to implement and enforce the Congressional Accountability Act (CAA) of 1995, to discuss how Congress could ensure that full coverage of the Americans with Disabilities Act and the Rehabilitation Act is extended to all instrumentalities of Congress, including the General Accounting Office, the Government Printing Office, and the Library of Congress.

NCD Participated in IDEA Meeting
June 4, 2001, Washington, D.C.

A stakeholder coalition group—Parent Training and Information Centers, National Association of Protection and Advocacy Systems, National Association of State Directors of Special Education, and Part C/Early Intervention lead agencies—working with the U.S. Department of Education, Office of Special Education Programs (OSEP) and NCD in refining OSEP's process for monitoring and enforcement of IDEA conducted a collaborative effort to improve results for children and youth with disabilities and their families. The stakeholder coalition group developed a plan to be carried out and seeks input about both the product and the process that created it.

NCD Releases Disability Status Report
June 14, 2001

NCD released its annual *National Disability Policy: A Progress Report* (www.ncd.gov/newsroom/publications/progressreport2000.html), confirming that despite great strides toward equality, people with disabilities still confront major barriers of discrimination and suffer the consequences of weak federal enforcement.

Because of the persistency of these barriers to equal opportunity, NCD believes that the president and Congress must set a standard of greater federal commitment to deliver on the promises of disability and other civil and human rights laws.

The report uses as benchmarks the recommendations for change made by disability leaders from throughout the country and captured in the 1996 NCD document *Achieving Independence: The Challenge for the 21st Century* (www.ncd.gov/newsroom/publications/achieving.html). These recommendations—elaborated on in subsequent annual progress reports—reflect a wide array of public policy areas designed to advance inclusion, empowerment, and independence of people with disabilities of all ages from diverse backgrounds consistent with the vision of the Americans with Disabilities Act of 1990 (ADA).

The report covers the period November 1999 through November 2000, the end of the 2nd Session of the 106th Congress. It reviews federal policy activities by major issue areas, noting progress where it has occurred and making further recommendations where necessary. The recommendations apply to the executive and legislative branches of the Federal Government.

NCD Releases Accessible Technology Report
June 21, 2001, Washington, D.C.

On June 21, 2001, the day Section 508 regulations went into effect, NCD held a news conference at the National Press Club in Washington, D.C., to highlight the release of its report *The Accessible Future* (www.ncd.gov/newsroom/publications/accessiblefuture.html. Among other things, the report found that access to electronic and information technology (E&IT) is a civil right and there is a need for a national accessibility policy.

Speakers at the event included Bonnie O'Day, Ph.D., NCD member; Ethel D. Briggs, NCD executive director; David M. Capozzi, director, Technical and Information Services, U.S. Architectural and Transportation Barriers Compliance Board; Cheryl Cumings, minority outreach coordinator, Massachusetts Commission for the Blind; and Laura Ruby, program manager, Regulatory and Industry Affairs, Microsoft Accessible Technology Group.

Panelists included Mary Brooner, director of telecommunications and strategy, Global Government Relations Office, Motorola; Deborah Cook, director, Washington Assistive Technology Alliance; Denice Gant, program director, Hewlett-Packard Accessibility Solutions; Susan K. Palmer, associate director, regulatory affairs, Cingular Wireless LLC; Kelly Pierce, disability specialist, Cook County State's Attorney's Office; Greg Pisocky, civilian agency liaison, Government Systems, Adobe Systems Incorporated; and Michael Takemura, director, Accessibility Program Office, COMPAQ Computer Corporation.

NCD issued an appeal to the Federal Government, private industry, and consumers to join forces to increase access to E&IT for people with disabilities. The appeal stems from the reality that increased access will improve the quality of life for people with disabilities. A strong partnership among the government, private industry, and consumers will accelerate what all Americans desire, which is a better life—in this case, for people with disabilities.

NCD Submits Recommendations to House-Senate Education Conferees
July 19, Washington, D.C.

Before the first meeting of the House-Senate conference on the No Child Left Behind Act of 2001 (H.R. 1) education bill, NCD submitted recommendations to all House-Senate conferees. The House and Senate bills (H.R. 1, as amended and S. 1) include damaging amendments that would allow schools to remove students from the classroom and cease the provision of services to these students for behavior violations of school or behavioral code. A review of NCD research makes it clear that these amendments would thoroughly undermine the educational gains that have been made in this country over more than 25 years for students with disabilities. Both the House and Senate "discipline" amendments are inconsistent with research findings of NCD and with recommendations NCD previously submitted to Congress through assessment studies of the IDEA implementation. Students with disabilities need the guarantee of consistency in their education. The social cost of abandoning this guarantee is far too high to justify these amendments.

NCD, educators, students, and their parents have found that IDEA is a good, solid law. If IDEA were fully funded and implemented, classroom behavior would not be an issue for debate. Therefore, NCD recommended (1) removing the discipline amendments in both bills; (2) replacing them with assurances that appropriate training, supports, and services will be provided to teachers and students; and (3) accepting the full funding amendment, with language that instructs the Department of Education and the Department of Justice to work together to ensure full compliance with the law in every state.

NCD Participates in Government Technology Summit
July 23, 2001, Washington, D.C.

NCD delivered remarks at the National Summit on Accessibility for Government IT, which was sponsored by the Performance Institute. The presentation highlighted NCD's report *The Accessible Future,* access to electronic and information technology, which includes the Internet, the World Wide Web, and information/transaction machines.

NCD Releases Position Paper on Supreme Court Ruling in *Sandoval*
July 31, 2001, Washington, D.C.

NCD released its position paper *The Sandoval Ruling* (http://www.ncd.gov/newsroom/publications/sandoval.html) on the U.S. Supreme Court's decision in *Alexander v. Sandoval* and on its implications for litigation under the ADA, Section 504 of the Rehabilitation Act, and IDEA.

The Supreme Court of the United States issued a decision in *Alexander v. Sandoval*, 121 S.Ct. 1511 (2001), on April 24, 2001. The *Sandoval* case involved a class action claim brought by non-English-speaking residents of the state of Alabama against the director of the Alabama Department of Public Safety. The plaintiff class claimed that the department's offering

Alabama's driver's licensing exams only in English had the effect of discriminating against them on the basis of their national origin. The plaintiffs argued that such discrimination violated Title VI of the Civil Rights Act of 1964 and the implementing regulations promulgated pursuant to § 602 of the Act by the Departments of Justice and Transportation. Section 601 of the Civil Rights Act prohibits discrimination on the basis of race, color, or national origin in federally funded programs. 42 U.S.C. § 2000d. Section 602 authorizes federal agencies to issue regulations to effectuate the requirements of § 601. 42 U.S.C. § 2000d-1. A bitterly divided Court ruled 5 to 4 that there is no private right of action to enforce the disparate impact regulations promulgated under Title VI. That means that private individuals do not have the right to file lawsuits under Title VI alleging that they have suffered disparate impact discrimination by recipients of federal funds.

NCD Files Amicus Brief with U.S. Supreme Court
August 31, 2001, Washington, DC

NCD filed an amicus curiae brief with the Supreme Court for the respondent in the case *Toyota Motor Manufacturing, Kentucky, Inc. v. Ella Williams* (No. 00-1089) (http://www.ncd.gov/newsroom/publications/toyota_amicus.html), which presented the question whether "an impairment precluding an individual from performing only a limited number of tasks associated with a specific job qualifies as a disability." Toyota argued that a plaintiff must be totally unable to do even modified tasks in order to be "substantially limited" in manual tasks and/or working, thus qualifying for ADA protection. NCD argued that Toyota's position demonstrates the erroneous view that Congress intended to extend ADA protection only to the "truly disabled" (i.e., those who are so severely restricted that they are unable to meet the essential demands of daily life). NCD argued that the clear guidelines provided by the Court in *Sutton v. United Airlines, Inc.*, 527 U.S. 471 (1999), *Murphy v. UPS*, 527 U.S. 516 (1999), and *Albertson's, Inc. v. Kirkingburg*, 527 U.S. 555 (1999) would allow a jury to properly find that Williams is "disabled" within the meaning of ADA because she is significantly restricted as to the condition, manner, and duration of performing manual tasks compared with the average person in the general population.

ADVISORY COMMITTEES

NCD has four advisory committees. They are the Cultural Diversity Advisory Committee, International Watch, Technology Watch, and the Youth Advisory Committee. All NCD advisory committees are governed by the Federal Advisory Committee Act (FACA), 5 U.S.C. App. 2, which was enacted to promote good government values, such as openness, accountability, and balance of viewpoints consistent with administrative efficiency and cost-containment.

The following is a summary of the activities of NCD's advisory committees:

Cultural Diversity Advisory Committee
Established during FY 2001, the purpose of NCD's Cultural Diversity Advisory Committee (www.ncd.gov/newsroom/advisory/cultural/cultural.html) is to provide advice and recommendations to NCD on issues affecting people with disabilities from culturally diverse backgrounds. Specifically, the committee will help identify issues, expand outreach, infuse participation, and elevate the voices of underserved and unserved segments of the nation's population. This will help NCD develop federal policy that will address the needs and advance the civil and human rights of people from diverse cultures.

This committee conducted its first meeting on July 31, 2001.

International Watch
The purpose of International Watch (www.ncd.gov/newsroom/advisory/international/international.html) is to share information on international disability issues and to advise NCD on the development of policy proposals that will advocate for a foreign policy that is consistent with the values and goals of the Americans with Disabilities Act. International Watch has two working groups: International Convention on the Human Rights of People with Disabilities and Inclusion of People with Disabilities in Foreign Assistance Programs.

Meeting dates:

September 20, 2001
September 6, 2001
July 19, 2001
June 29, 2001
May 30, 2001
May 4, 2001
April 26, 2001
April 12, 2001
March 14, 2001
March 8, 2001
February 15, 2001

Technology Watch
The purpose of Technology Watch (www.ncd.gov/newsroom/advisory/technology/technology.html) is to assist NCD in monitoring, analyzing, and promoting technology access issues. The intent is to make the information superhighway accessible to and usable by people with disabilities by recommending government policies and industry practices that facilitate this vision.

Although Tech Watch did not meet formally during the fiscal year, it did provide advice to NCD on the development of its report *The Accessible Future* (www.ncd.gov/newsroom/publications/accessiblefuture.html).

Youth Advisory Committee
The purpose of the Youth Advisory Committee (www.ncd.gov/newsroom/advisory/youth/youth.html) is to provide advice to NCD on various issues such as NCD's planning and priorities. NCD is seeking this type of input to make sure NCD's activities and policy recommendations respond to the needs of youth with disabilities.

Meeting Dates:

August 6, 2001
March 14, 2001

CONGRESSIONAL TESTIMONY

In FY 2001, NCD provided formal testimony to Congress on two occasions:

February 28, 2001, testimony submitted to the U.S. House of Representatives.
NCD testified (www.ncd.gov/newsroom/testimony/01testimony.html) before the House Committee on Government Reform on the Individuals with Disabilities Education Act.

April 18, 2001, testimony submitted for the record of the U.S. Senate.
NCD submitted written testimony (www.ncd.gov/newsroom/testimony/bristo_4-18-01.html) on patients' rights principles to the Senate Committee on Finance hearing (March 27) on Society's Great Challenge: The Affordability of Long-Term Care.

INFORMATION DISSEMINATION

Information dissemination continued to grow at record levels for NCD, as it responded to thousands of telephone calls, e-mail messages, and letters from concerned people and organizations about disability issues. In addition, NCD published its monthly newsletter, *NCD Bulletin*, which reaches more than 15,000 people and organizations. All NCD publications are available in alternative formats, such as braille, large print, and audiocassette. This information is also available at NCD's award-winning Web site (www.ncd.gov), which now receives more than two million hits per year.

NCD QUARTERLY MEETINGS

As required by Section 400(3)(c) of the Rehabilitation Act of 1973, as amended, NCD met on four occasions during FY 2001. In addition, NCD also met once by conference call.
August 6–7, 2001, Washington, DC
July 11, 2001, conference call
May 21–23, Arlington, VA
February 5–6, 2001, Myrtle Beach, SC
December 4–5, 2000, San Diego, CA

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Appendix
Mission of the National Council on Disability

Overview and Purpose

The National Council on Disability (NCD) is an independent federal agency with 15 members appointed by the president of the United States and confirmed by the U.S. Senate. The overall purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or significance of the disability, and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

Specific Duties

The current statutory mandate of NCD includes the following:

- Reviewing and evaluating, on a continuing basis, policies, programs, practices, and procedures concerning individuals with disabilities conducted or assisted by federal departments and agencies, including programs established or assisted under the Rehabilitation Act of 1973, as amended, or under the Developmental Disabilities Assistance and Bill of Rights Act, as well as all statutes and regulations pertaining to federal programs that assist such individuals with disabilities, in order to assess the effectiveness of such policies, programs, practices, procedures, statutes, and regulations in meeting the needs of individuals with disabilities.
- Reviewing and evaluating, on a continuing basis, new and emerging disability policy issues affecting individuals with disabilities at the federal, state, and local levels and in the private sector, including the need for and coordination of adult services, access to personal assistance services, school reform efforts and the impact of such efforts on individuals with disabilities, access to health care, and policies that act as disincentives for individuals to seek and retain employment.
- Making recommendations to the president, Congress, the secretary of education, the director of the National Institute on Disability and Rehabilitation Research, and other officials of federal agencies about ways to better promote equal opportunity, economic self-sufficiency, independent living, and inclusion and integration into all aspects of society for Americans with disabilities.
- Providing Congress, on a continuing basis, with advice, recommendations, legislative proposals, and any additional information that NCD or Congress deems appropriate.
- Gathering information about the implementation, effectiveness, and impact of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.).
- Advising the president, Congress, the commissioner of the Rehabilitation Services Administration, the assistant secretary for Special Education and Rehabilitative Services within the Department of Education, and the director of the National Institute on Disability and Rehabilitation Research on the development of the programs to be carried out under the Rehabilitation Act of 1973, as amended.
- Providing advice to the commissioner of the Rehabilitation Services Administration with respect to the policies and conduct of the administration.

- Making recommendations to the director of the National Institute on Disability and Rehabilitation Research on ways to improve research, service, administration, and the collection, dissemination, and implementation of research findings affecting persons with disabilities.
- Providing advice regarding priorities for the activities of the Interagency Disability Coordinating Council and reviewing the recommendations of this council for legislative and administrative changes to ensure that such recommendations are consistent with NCD's purpose of promoting the full integration, independence, and productivity of individuals with disabilities.
- Preparing and submitting to the president and Congress an annual report titled *National Disability Policy: A Progress Report*.

International
In 1995, NCD was designated by the Department of State to be the U.S. government's official contact point for disability issues. Specifically, NCD interacts with the special rapporteur of the United Nations Commission for Social Development on disability matters.

Consumers Served and Current Activities
Although many government agencies deal with issues and programs affecting people with disabilities, NCD is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, veteran status, or other individual circumstance. NCD recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing the concerns of people with disabilities and eliminating barriers to their active participation in community and family life.

NCD plays a major role in developing disability policy in America. In fact, NCD originally proposed what eventually became the Americans with Disabilities Act. NCD's present list of key issues includes improving personal assistance services, promoting health care reform, including students with disabilities in high-quality programs in typical neighborhood schools, promoting equal employment and community housing opportunities, monitoring the implementation of the ADA, improving assistive technology, and ensuring that those persons with disabilities who are members of diverse cultures fully participate in society.

Statutory History
NCD was initially established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed NCD into an independent agency.

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